

"...She moves freely without fear, giving free reign to her instinct, making her hand follow some mysterious movement taking place in the silence of her mind...these pictures communicate in the language of forms and any attempt to decipher them in words must end in absurdity."

Krishen Khanna, artist

"...her contact with Australian Aboriginal art has awakened something primordial in her. So she transforms whatever she experiences into dreamtime, the paradise of harmonious shapes, colours, and, at moments, deep sensitivities..."

Keshav Malik, art critic

"I ...was struck by the sheer verve and sureness of touch in one as young as she. She has the characteristics of a true expressionist painter and her work, far from expressing any hint of her disability, bears out the astonishing but well-known fact that sometimes in such cases an unusual and superior talent manifests itself. Radhika seems to fall into that category of 'rarities'..."

Anjolie Ela Menon, artist

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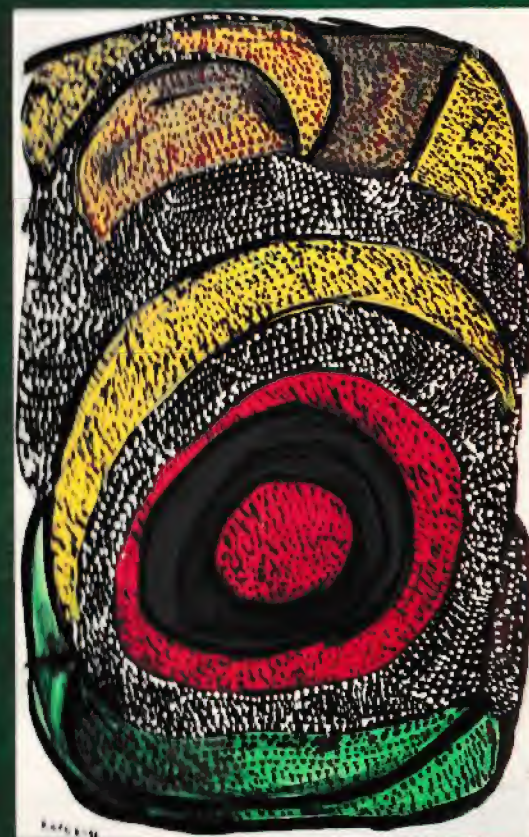
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Memoirs

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CLIMB EVERY MOUNTAIN

RADHIKA'S STORY



I N D E E R A C H A N D

This is a biographical story of human interest about the challenges and rewards of bringing up a daughter with Down's Syndrome. Ignorance has led to stigmas and taboos, which have put a lot of unnecessary social pressure not only on families but equally on people with mental handicap. Radhika's story is one of continued struggle, but also of heart-warming support, and ultimately of triumph. Radhika has challenged the values, expectations, and very way of life of those around her, and her creativity has surpassed that expected of even a 'normal' person.

At her birth, 24 years ago, there was no writing of this kind in India, and her family had to send for such stories from abroad. Even today, there are only very few books on real life experiences. Radhika's presence has enriched her family, and her story will help to dispel some of the darkness surrounding mental handicap.

CLIMB EVERY MOUNTAIN

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RADHIKA'S STORY

Indeera Chand



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*Radhika, determinedly yourself, may you
inspire others as you have done us*

Preface

Radhika, our third daughter, born with Down's Syndrome was twenty in 1992 when I decided to write her story. We had returned to Delhi two years before to find some increase in the number of facilities available, but not enough change in attitudes and expectations. Ten years abroad in Hong Kong and Sydney had shown us just how important this change is if there is to be real progress towards normalization and acceptance in society of the learning disabled. I have learnt that this process must start early and from within the family, progressing in widening circles so that eventually the handicapped are able to participate in community life in a mutually beneficial manner.

The effects of the forty-seventh chromosome which delays and handicaps both mental and physical development, have been a great challenge to us all. In learning to cope, Radhika has taught us many things. She showed us the way out of our initial pain and guilt and fear and helped us to overcome these feelings. The process has been slow and arduous. While she strove to learn to crawl, sit, walk, eat, bathe, dress and talk, we strove to learn acceptance, patience and the value of encouragement and praise. We had to learn to accept her slower pace, to celebrate her successes however small, as and when they came. It has been relentlessly demanding but nonetheless very rewarding.

Most of all, Radhika has shown us another side of ourselves, another aspect of human endeavour, another set of

values. She has made us more sensitive to and more accepting of the differences in human beings. She has enriched our family life. Given the opportunity, she and others like her could enrich society as well.

In writing Radhika's story, I want to share our experience with families who may be cast down and looking for a way to cope. I also hope to reach professionals concerned with the care and education of the disabled, sharing with them the challenge and reward we have experienced. Finally, I hope the story will be of interest to the general public who must become aware of the lives and aspirations of people with a handicap, to know and accept them as individuals with their own potential and contribution to make, and not to shun or pity them.

After I found out that Radhika had Down's Syndrome, I remember searching desperately for stories of other families in similar circumstances. I found nothing. Nothing at all was being written in India at the time. The subject was taboo, barely acknowledged, let alone written about. Even today, there is hardly a book written by parents. However, personal accounts in books from abroad gave me great comfort and strength, and I am sure this is true for all families. When the subject of handicap can be written about, shared and aired, its veil of secrecy will begin to lift, and the 'shame' felt by families and inflicted upon the handicapped will be laid to rest once and for all.

When parents overcome the shame of having a handicapped child, a lot can be gained. We have never felt ashamed of Radhika, although at first we did fear 'rejection' from family and friends. From the very beginning she has been an integral part of our family and our lives, gradually fashioning a very special niche for herself. Encouraged by educationalists with a vision and belief in her, she and we have come a long way — further than we had ever imagined possible.

Many people have supported and advised us, but there are two, without whom the first steps forward could not have been taken. Bansri Maniar, Radhika's first paediatrician, whose concern and sound commonsense sustained us and led us to Dina Guha — her first special educationalist. Dina's wisdom and spirit enthused us all, and with her extraordinary faith in 'Radhika *can* do', set us off on the only path we could take in the circumstances. Finally, a special mention to Sydney's Cromehurst Special School which believed Radhika's potential was unknown and therefore not limited, showing us and Radhika herself, how much more she was capable of learning and doing, and especially Katrina Bull, Cromehurst's art teacher, who discovered and nurtured Radhika's talent. To all these very special people we are deeply indebted and grateful.

My heartfelt thanks to Ramesh, my husband, for his staunch and exemplary support through all these years, and for patiently typing and retyping this manuscript. And to Sandhya and Aarti, my daughters, who played, taught, teased, encouraged and loved Radhika, making our family life 'normal' and close.

*Indeera Chand
New Delhi
April, 1996*

Two Essays by Radhika

My two best friends have been Dad and Mum. When I was a small girl I ran to Dad and he picked me up and tickled me and threw me up in the air. I loved it and it made me laugh. I remember my Mum to be there for me all the time. She gave me a bath. She dressed me, fed me and took me to the park. At night Mum read me a story and Dad tucked me into bed.

Sandhya and Aarti were in boarding school. They came home for holidays when we had a good time together. All three enjoyed doing jigsaw puzzles.

I remember a naughty thing I used to do as a small girl. In the afternoon when everyone was sleeping I went to the kitchen and started playing with the cups and plates. And sometimes they would break. Mum would wake up hearing the noise but I always managed to run away and creep into bed and pretend to sleep. So Mum never found out.

Another time in Hong Kong I started driving Dad's car in the garage. The car moved out of the garage and crashed into the flower pot and stopped. So I was saved. Dad and Mum came running out to find me crying.

I remember Purobie in Calcutta who taught me to read. When we went to Sydney I was more grown up. I remember my school in Sydney where I met my best friend Arni. Katrina was my art teacher who taught me to paint. She was very soft-spoken and she showed me different ways to paint. Sometimes I painted

with a brush, sometimes with a roller, sometimes dipping thread in ink. I loved my art class and I wanted to paint all the time.

Then one day they put my painting up in the Variety Club Hall for an art exhibition and dinner. Everyone liked my painting. My Dad and Mum came to see it and they were very happy. That's how I became an artist. It makes me feel I am more special than others. I feel proud that I have done something to make others happy. I like it when they want to put up my paintings in their homes. My home is filled with my paintings and I feel good to see my Mum and Dad feel proud of their daughter when guests come to the house and say, "Who has done these beautiful paintings?"

My sisters and I spent more time together in Sydney. We went for barbecues and picnics. All three of us shared a room. We played music and watched TV and drank lots of coke and coffee. I liked living in Sydney more because my sisters were at home with me.

I am now in Delhi. At first I did not like Delhi because I found the streets dirty and I could not understand the people speaking Hindi. But I have now made friends and I have a job in the school where I help the art teacher. I had my first exhibition in Delhi. I have lots to do in Delhi now and I love my home. I paint, cycle, watch TV, play badminton, go for walks, do my knitting and cross stitch, play the piano, sing and dance, read books, cook shepherd pie, chat with friends, look after *nani* and *dadiji*, and have fun with Mum and Dad and my sisters. So it is wonderful to be alive.



In my family of three daughters I am the youngest. I grew up with my two sisters and I always liked to do whatever my sisters

did.

When I grew up I knew I will not be able to go to college like my two sisters. As I was born with Down's Syndrome I could not read and write so much and so fast, like them. I felt sad and I think my Mum and Dad were also disappointed that I was not going to be like my two sisters who were smart and clever in studies.

When I was thirteen I went to a special school in Sydney. That's when I started painting. My art teacher taught me many ways to paint. Sometimes I used a brush other times a roller. I also used a thread dipped in ink. I began to enjoy painting.

As I didn't have to study hard for exams I had so much time to experiment with painting. I made lots of dots and lines — splashed with a spray gun. I think I was lucky not to get bogged down by studies. My sisters never had time to do anything like this.

Everybody started saying "how well Radhika is painting." My Mum and Dad were also very happy to see this new talent. When my painting was put up in the exhibition for the first time, they felt very proud of me. That made me feel happy, good and fulfilled because I could do something which gave others so much joy.

So what if I could not go to college. I could be a painter — have exhibitions and sell my paintings. I could also teach small children.

This is what I'm doing now. I live in Delhi. I am working as a teacher's assistant in Vasant Valley School. I find time to paint in my spare time.

I have had a solo exhibition. I have won prizes in art competitions and I keep selling my paintings all the time.

I love my sisters very much. They have both done well.

Sandhya is in management, Aarti has a Ph.D in micro-biology. I am very proud of them and they are very proud of me because they can't paint like me — so they say. But I know that they never had the time to even try!

Redhita Chand

Chapter One

Ramesh and I met in Srinagar in the summer of 1955 and fell in love. Our family backgrounds were very different — Ramesh the only son of Hindu parents, and I, a Christian. When he told his family of our decision to marry me, they were disappointed. His mother visited my family in Hoshiarpur and as is the Hindu custom, had a pundit read Ramesh's *janam kundli*. According to the horoscope, Ramesh would marry a girl of his choice, whose name would begin with the letter 'I' and who would belong to a different religion. This reading somewhat allayed his parents' fears, and Ramesh and I were married in December 1961.

Ramesh worked for a British bank in India and had been posted to Delhi after short postings in Calcutta and Bombay. Our first home in Delhi was where we had Sandhya in 1963 and Aarti in 1965. In 1969 Ramesh was transferred to Calcutta.

It was time to have our third child. Since this was to be our last, and I had had a long uterine history, I wanted the obstetrician to check me out and give me the green signal. I told him that my very first pregnancy had ended in a three-week's premature but stillbirth. The following year we had Sandhya. For the next two years I used an IUD and after Aarti, the pill and two sets of IUDs. In 1970, I had a series of haemorrhages and had to be hospitalized for a D & C. The doctor found the IUD out of position and a two-month foetus dead and disintegrated, which had to be cleaned out. He gave

me a physical examination and told me to go ahead.

That very month I conceived. But in the third month I contracted German measles and had to have an abortion. The same doctor told me it would be safe to conceive again after three months. I was thirty-three — I don't know why I felt the need to get a medical okay. After the abortion, I often wondered if we were not meant to have a third child. Ramesh did not, however, accept this and soon after the prescribed three months I was pregnant again.

In August of the same year Ramesh was posted to Bombay. I did most of the packing and travelled with Sandhya and Aarti by train to Bombay.

It was a thirty-six hour journey and on the first night I had a little haemorrhaging. I remember my fear. Sandhya and Aarti were as good as gold while I lay down with my feet raised and prayed that we would arrive quickly, before any further bleeding.

It was a great relief to reach Bombay and see Ramesh (who had flown in earlier), his sister and mine at the station. We got in touch with one of Bombay's leading obstetricians who advised bed rest and some pills. The bleeding stopped but I was unnerved. I started having dreadful thoughts and frightening dreams. So persistent were these that I asked the doctor what he would do if I produced a 'monster'. He told me very clearly — I still remember his words — "We don't do all we can to save the baby". On twenty-fifth March 1972, I went into labour. It had been an uneasy pregnancy mentally and physically, and it was a very difficult dry labour and breech delivery. *The doctor did everything possible to save the child.*

The baby was cyanotic at birth and there was no cry. Doctors and nurses were flapping around, the atmosphere was tense and anxious. Finally they asked Ramesh if we had a family paediatrician who could come immediately. Bansri came as soon as she could. I sensed the anxiety but vaguely,

and finally was wheeled out of the delivery room. The sister on duty explained that the baby was denied oxygen at birth. Bansri advised an oxygen tent for the baby and then came in to see me. They were all worried about the baby, but no one said anything more to me. Though full term, she looked small and shrivelled. Her skin was like the dried scales of a sun-baked fish, she could hardly open her eyes, her cry was extremely feeble and in that first week at the hospital she had repeated attacks of cyanosis. In hospital I learnt that the placenta was unhealthy and not fully developed, and that the cord was very short.

Bansri looked in two or three times a day, and once ordered a chest and lung X-ray as the baby had turned very blue. She could not suckle at the breast and had to be fed by a dropper. The irony was that I had an endless supply of milk that would not dry up despite injections and pills. It was so wrong — everything seemed wrong. In that first week my concern was for her survival. I did not let myself think of anything else. I remember praying for her life. Yet I asked the sister in the ward why the doctor had done so much to save her life. She told me he had a reputation to keep up.

Deep down I must have known that a lot would be wrong with Radhika. Lack of oxygen at birth is a serious situation. On the one hand I kept wanting her to survive, on the other I kept asking why the doctor had saved her. This duality of emotions plagued me for nearly four years. It was not shame I felt. Rather, I was consumed with the 'burden' and complete ignorance of how I could cope with it. Radhika was nearly three when we first met Dina. I remember asking her frequently how long such children survive; someone, or was it Dr. Spock, said they usually had a short life span. I needed to know exactly how short.

One night I dreamt I had put Radhika in a box, shut the lid and hidden the box under my bed. After a few days I

opened the lid a wee bit — she sighed and I quickly shut the box. I had the same dream for three consecutive nights. I was appalled and haunted by it.

Dina Guha, an extremely wise and experienced US-trained educationalist, was by now helping us with Radhika's early training. Eventually I confided in her. She listened carefully, saying that it was quite natural to want to be free of Radhika and that I should neither feel guilty nor blame myself for having such dreadful thoughts. Negative thoughts and emotions are to be expected, she explained. It was good to be able to voice them and hear from Dina they were only natural and that, once I accepted Radhika, these thoughts would go away. It took me a long time to accept my own feelings. This knowledgeable and wise friend helped me to accept and overcome the negative feelings in myself, which was necessary before I could go forward.

The very first night after Radhika's birth Ramesh had looked through Dr. Spock at home and then gone to see Bansri. Bansri told him Radhika was certain to have mongolism, but the damage could only be assessed as she grew up. They decided to keep this fact from me until I was stronger and better able to receive the news. Though my parents were with us, and Ramesh had a sister and brother-in-law in Bombay, he did not share this news with anyone lest I should hear of it inadvertently. To this day I cannot understand how he coped all on his own. When I ask him, he is loathe to recall his emotions. Suffice it to say that he gave me time to recover from the physical trauma of the birth, and carried that knowledge alone for nearly six months, until I found out slowly for myself.

After a ten-day hospital stay we brought the baby home. She was too delicate and I, too exhausted to look after her on my own. We appointed a nurse for the first month. Radhika had to be protected from infections and watched for

cyanosis. Bansri came every two or three days to check on her and me. Very, very slowly Radhika began to gain strength. Sandhya — nine, and Aarti — seven, observed her from a distance. They had wanted a sister and accepted this one as 'weak'.

After the first month when I began to do more for her, bathe and feed her, I began to realise how very different her responses were compared with those of Sandhya and Aarti at the same age. I still wasn't ready to find out the truth though I felt anxious all the time. The first six weeks over, we visited Bansri at her clinic every two weeks. Bansri checked her weight, height and the circumference of her head at each visit. She also checked her reflexes and head support and maintained a complete record. Her advice was to 'treat her normally', talk and smile and stimulate her as much as possible.

What a painful pleasure it was when, about two months later, we were able to cuddle her without fear, to watch her closely! With her small round head, the hair growing thin and straight, slanted eyes, stubby nose, she looked Chinese and I called her 'Mao'. Did I have any suspicion? If I did, I suppressed it. I was fearful, but this may have been my subconscious way of rejecting the awful truth for as long as I could.

The truth, however, must have begun to dawn over the next three months. She could not hold up her head, or reach and grasp with her hands, or follow moving objects with her eyes. Her milestones were well behind the average. Her head measurement was also well below average. All this made me aware that more was wrong than merely the physical weakness. She was slow to recognise, babble, turn over. Nor was she as active as Sandhya or Aarti had been at the same age.

In September, Ramesh had to attend a two-week course in Calcutta. He was extremely keen for my mother to come

from Chandigarh to be with me while he was away. It seems that I had blanked out the possibility of mental retardation for as long as I could. Now, slowly it had become a distinct reality. One afternoon I remember picking up Spock and reading the section on difficult births: lack of oxygen, brain damage, mongols. As I read the section on mongolism, my fears were clearly confirmed. The description of the appearance and facial characteristics fitted my 'Mao' exactly. I looked up Mongol in the dictionary. 'Idiot' it said. The shock, the panic was intense. What had I done to bring this upon us? Had my smoking been responsible, was I guilty, were we, after all, not meant to have a third child, were those measles a warning? The slight haemorrhaging on the train, was that my body's attempt to miscarry an abnormal foetus? What did the future hold, how long would she live, and for how long would my life be turned upside down by this little freak? Perhaps, the nightmares and monstrous thoughts during my pregnancy were portents, signs that had been dismissed by my doctor. Were we destined to have her then? Had she come into our lives to teach us something? Night and day I was plagued with such thoughts.

At last everything began to fall into place. My heart ached, my head burst, I felt a stone in my throat. I wept. Waves of pain, tears, choking ache overwhelmed me. We had ignored all our premonitions. The doctors had helped us to have her, and here we all were, with no choices left, except to do what we could to make the best of the situation.

Ramesh stood solidly by me. Now that I also knew, at least we could share our shock and grief. I will never forget the day when looking at me with sudden realisation, he said quietly, "Perhaps she has come to teach us humility, so that we may be more tolerant of other people's weaknesses."

I wondered why the Calcutta doctor never mentioned the risk. As I learnt more about the possible causes of a Down's

Syndrome baby, I definitely felt I had not been warned despite having asked if it was 'safe' to conceive. No doctor can predict accurately and yet they should tell what they know. Perhaps they don't concern themselves with more than just their immediate task. In modern times, when women are using contraceptives, abortion is legal and women are having babies at a later age, it seems all the more important to make women aware of all the risks. Personally I would rather have been warned and then made an informed conscious decision.

The Bombay gynaecologist had allayed my fears and then done all he could to save the baby's life at birth. On a postnatal visit to him he had assured me that she would be 'all right'. Did he care? Or did he deliver and save life, no matter what? I felt betrayed by both my doctors, yet I didn't take it up with either. Maybe the hurt and the pain were too much. Perhaps there was nothing to be gained. These thoughts persisted and rankled for years.

We were members of the Breach Candy Hospital and Nursing Home Benefits Scheme, a health insurance Ramesh's employers subscribed to for employees and their families. Radhika's birth, our stay in the hospital, and all the extra nursing and tests had cost much more than a normal delivery. Though Ramesh had to make cash payments, we felt sure it would be covered by insurance. We were dismayed to find that the scheme would not cover Radhika's expenses because she was not 'normal'. This was a shock and the first rejection from society. We felt battered, but resolved almost instinctively that we could and would survive. Ramesh did take it up with the hospital insurance committee, but to no avail.

In September my mother came from Chandigarh to spend time with us, to help me find my feet and give me the support I needed desperately. She stayed on with the girls so that Ramesh and I could take a two-week holiday down South after his course. It was wonderful to get away, knowing that

she was there, devoted, sensible, loving and capable.

Our first Diwali was a very painful one. For Sandhya and Aarti's sake, we had to light our candles and *phooljharis*. Our hearts were heavy as stone. I went to the balcony and wept bitterly. Both girls came up almost at once and stood with me. "Don't cry Mummy, she'll be all right," they said. I can never forget their innocent faith and their spontaneous expression of support.

For months after this I used to go over details of the pregnancy and birth. I read relevant sections of Spock dozens of times and wanted to hear from whoever I could about other such children. I must have gone about the daily routine of family life half dazed, half crazed. It is difficult to relive those first months and to recapture those early thoughts and feeling, but the overwhelming feeling was one of being trapped. There was no escaping the responsibility and no knowing then what this would entail.

In October/November of the year following her birth, we began to plan our first holiday with Radhika. We would visit our families in Chandigarh, breaking journey with friends in Delhi. I was consumed with fear and anxiety. How would they take the news, would we still be welcome in their homes, would they make a difference between Sandhya, Aarti and Radhika? For weeks I tortured myself. Then one day I picked up courage and broached the subject with Ramesh. "Of course we will tell everyone the truth about her". He was so clear, so certain that he dispelled one of my major fears. It was so much easier to face the holiday knowing that we need not hide anything. As for people's reactions, we would have to wait and see.

Even though I knew I had Ramesh's complete support and we had agreed on how to handle the visit, it proved an extremely difficult trip. I was very tense all day and could not sleep at night. Each day made it worse and after nearly

ten sleepless nights, Ramesh rang up a friend in Bombay who advised I take regular doses of Kali Phos, the biochemical remedy for mental and emotional stress. Finally this and the naturalness of family and friends helped to break the vicious circle. Everyone wanted to know. Their interest and concern was genuine. They made no distinctions between the girls, they accepted all of us with their usual warmth and this helped me regain my faith and confidence. In Chandigarh too, my in-laws were perfectly natural, accepting and loving. I felt no judgement, no accusation, no blame, either overt or covert.

My mother and father had been with us through the birth, and both knew the whole case through mother who had spent time with me after I 'found out' in September. My father loved watching Radhika on the sitting-room carpet where she lay each evening, moving a little, babbling a little. One evening he said, "If only she could remain a child this small she would be delightful". And so began the healing process, eased by a thoroughly sensible attitude by all our near ones. No one had 'rejected' her or us. I was reassured and could begin to start on the long hard journey towards acceptance.

It seems to me that the initial pain, guilt, and the wishing away of such a mishap is normal. But overcoming these feelings is essential for the health and well-being of the handicapped child as well as of the family. The more open we are, the quicker is the process of our own acceptance and that from society. The child will sense rejection and retire into a shell unless we work continuously with our own feelings and inhibitions and towards the development of the child. If the child is allowed to build on its small successes, if these are understood as such, praised and valued, the child blossoms into an acceptable, caring member of the family and of society.

Radhika has shown us this. She has given us a great

measure of fun, laughter, joy and happiness. Her caring, loving sensitivity to people has endeared her in her own right. Though I may ache for her and torture myself for all the normal things and relationships she will never have or know, I realise that she doesn't brood. She is content and happy in the life and love she has. She seems to hold no grudges and no deep sadness.

Chapter Two

At nine months Radhika was only just beginning to crawl and to pull herself up to a sitting position. She made a few recognisable sounds but had no vocabulary. Standing with support came at one year, walking a few steps without support came at one year and eight months and the pincer grasp developed at thirteen months. All these delayed milestones were indications of slow development. Bansri encouraged us to continue treating her normally, letting her crawl, walk, explore, do as much as possible. It was very important to stimulate and encourage her movements, reaching, grasping, holding and throwing. The hypotonia, or slack muscles, had to be exercised and strengthened in every possible way.

Despite all these efforts we were nagged by doubts. We did not know for certain whether we were giving her our best. Nor had we really accepted the verdict on her. Bansri saw her regularly and advised us most willingly and well but we seemed to need something more. There was, in Bombay, a very well-known paediatrician. We were nervous as his words was going to be final. He would declare her 'mongol' or not.

He was brief and to the point. It didn't take him more than a few minutes to examine her and declare her 'Down's'. He looked at the head, the creases on her palms and soles. I remembered Bansri doing this as well. "She has Down's Syndrome. She will never go to college," he said, "but she will probably learn to walk, talk and take care of herself." He had nothing more to say.

Our fate having been sealed, we could not ask any of our questions. He had no advice on how to start the training, or who could help, no list of specialists we could consult. Only the bald verdict. We gathered ourselves up and left. He did prescribe vitamins and thyroid supplements, if I recall correctly. These were not going to change her condition, we had to accept that. Afraid of overdosing, we decided not to give them at all.

The struggle within me had two definite threads. First, non-acceptance. Could something be done to change her status by medicine or miracle? And second, a reluctant acceptance of her unalterable condition. While we did not want to run from pillar to post, we didn't want to sit back and look for no miracle at all.

Narayan Baba, a holy man, was visiting the home of a friend. We were asked to bring Radhika for his *darshan*. Though Ramesh was keen to go I felt we would not be able to follow his instructions in a spirit of belief, and only reluctantly agreed. We wrapped up Radhika and drove to Colaba wondering what the result would be.

We brought Radhika up to him, and he held her in his hands. "Her neck is weak, did you look at a solar eclipse during your pregnancy?" he asked. He wanted us to rub a certain oil after her bath, and then smoke her in the *sigri* smoke of *luban* and a special *vibhuti*. All this we did, but we knew that the syndrome would not go away. Still, we felt better for having tried even this. The *vibhuti* had a good clean smell and perhaps she did not get as many coughs and colds and upper respiratory infections as she was prone to earlier.

The first year was by this time nearly over. Radhika was certainly physically stronger though she still got repeated attacks of diarrhoea and, though less frequently, coughs and colds. She had been given the necessary immunizations of smallpox, triple vaccine and polio. The BCG was not given

as her Mantoux test was negative. She weighed 14 lbs 11 ozs, was 26" in height and the circumference of her head measured 16 1/2".

We wrote to friends and relatives abroad to send us literature on children with Down's. The papers from Canada were the most enlightening. There were pictures and stories of other, similarly affected children, of how their parents had coped, how most of them could be trained in self-care skills. Some were even educable. One young adult had learnt to drive, passed the normal test, and was a most careful, responsible driver, sought after by trucking companies who transported freight across Canada. These books and accounts gave us hope and courage. I read everything I could get hold of — on every kind of 'handicap', cerebral palsy, autism, Down's.

Though I was beginning to gain courage, I needed a change and a break from the routine of Radhika and the house. I needed to get out and become interested in something outside the home, and forget for a while what weighed me down constantly. Ramesh encouraged me to meet the people running 'Mobile Creches'. They ran on-site creches providing health care, nutrition, *balwadis* and basic education for the children of construction workers.

I joined tentatively but then got increasingly involved. At first it was merely an escape from my own problem. Later it became a compelling interest in the lives of these exploited and underprivileged communities. This involvement which restored some of my confidence, made me look at other types of hardship and appreciate that I was neither alone, nor singled out by misfortune.

Radhika, eighteen months old, was now toddling all over the flat. We played and talked with her as normally as possible. Throwing, rolling, catching a ball, and playing an easy hide and seek. She could follow simple commands and say

a few words with meaning. Though she had learnt to feed herself, we found she did not chew. We had managed to potty train her and she was generally dry during the day. Sandhya and Aarti were very fond of her, including her in their daily playtime activities.

At two years of age, Bansri advised us to take Radhika to a newly established institute in Parel where they would do a special blood chromosome study to determine the type of Down's Syndrome she had. I was nervous again — fearful of the result; almost as if I didn't want to know any more. When they took blood from her heel, Radhika began to cry a few seconds after the prick — a typically slow reaction. Three weeks later Bansri rang up to say they had taken the blood from the wrong place. Unwilling to put Radhika or myself through this ordeal once again, we decided not to repeat the test. At this stage all we knew was that Radhika had Down's and that nothing would change that. We did not realize the importance of this chromosomal study.

On our next visit to Delhi we consulted our family homoeopathic physician, Dr S.K. Roy. We explained everything we could. He gave us *puriyas* to start Radhika on once we got back to Bombay. This we did. In two days, one leg began to swell, redden and feel very hot. By the fifth day, her fever was a raging 104 and rising. The leg from the thigh down was burning hot, swollen hard and extremely painful, even to the touch. We rang Dr. Roy. He suggested we get a doctor to examine her heart and lungs. If they were all right, we should sit it out and watch the medicine act fully. The GP took one horrified look at her leg and warned it might have to be amputated if this went on. But the examination showed her heart and lungs were fine. Night and day we watched her, sponging her fever down every half hour. On the sixth or seventh day we rang Dr. Roy again. We could not endure this any longer. We were advised one more night of waiting, but

if we couldn't manage this, he gave us the name of the antidote. He was extremely satisfied with the reaction. It had affected only her lower limb, leaving all her vital organs untouched. That night when we could take no more, we gave her the antidote. It worked and we slept after seven days.

Eighteen years later, after I had studied some homeopathy in Australia, I understood what Dr. Roy had attempted and how the remedy had worked. Her vitality was weak. The remedy was meant to give her vital force a boost, and her reaction was the safest and best as it affected only a limb, leaving the vital organs safe. As she battled, she gained strength. We hadn't been able to see it through, but her resistance improved and she has remained fairly healthy since. She has not had any major illnesses, and though we have had to consult doctors from time to time, she has avoided allopathic treatment through most of her life.

The months passed, and though the pain of knowing she was subnormal never left us, it did begin to recede. Unsure initially whether she would even sit or walk, let alone feed herself, talk or play, we saw that she was very slowly learning normal activities. Each little step, so slow in coming, helped us to hope a little bit more. Underneath our normal behaviour with the girls and our family and friends and despite the slow gains, we had a constant nagging fear that the progress might suddenly come to a halt. The most agonizing part was this uncertainty.

Radhika was now two and a half years old. We were still taking her to Bansri for regular monthly checks. We found her not only good with Radhika, but good with us as well. She seemed to understand our initial shock and inability to accept. She gave us sound advice, put us in touch with the right people at the right time. It was now time to think of playschool. But first Bansri advised a visit to a clinical psychologist who would assess Radhika's intelligence levels.

The testing was arranged in April 1975, when Radhika was just over three years old. The tests administered were four in number — Seguin Form Board, Bender Gestalt Test, Vineland Social Maturity Scale and the Binet Kamat test of verbal intelligence. The conclusion was that while she had some difficulty with her speech, she appeared to be functioning at the level of about a mental age of two years and six months, which placed her in the "Borderline Mentally sub-normal range IQ=83".

Armed with this knowledge and the report, Bansri suggested we take Radhika to a Mrs Swamy who worked in the Sewri school for the mentally handicapped. So far I had not had the courage to visit any such school. Friends had suggested I go and had offered to go with me but I had not been able to, feeling it would be emotionally overwhelming. Now I had to go. Ramesh drove us there. He always went with me, knowing how vulnerable I was.

We saw children with various disabilities and in varying degrees. It was such a shock to know our Radhika was one of 'them'. There they were, all of them involved in different activities and fairly cheerful. However, Sewri was too far away from our home, and it was not practical to send Radhika there every day. Mrs Swamy read the report from the psychologist, offered to give us a short-term learning programme for Radhika whom she found 'friendly, sociable, cooperative and with a fairly good eye-hand coordination'. This much we had already gained. She suggested we contact Dina Guha, who lived on Warden Road not far from where we lived.

Part of the programme suggested by Mrs. Swamy was already being followed by us at home. But for a slow learner with a short attention span the method had to be different, and a special educator would be the right person to get the best results.

We did try and follow the entire programme at home. The

programme was divided into the three main areas of language, visual perception and motor co-ordination, and personal/social communication. It was also recommended that "short term exposures to informal play group situations would be beneficial." It seemed we would need a special educator and a playschool.

We discussed the possibilities amongst ourselves and decided to try first with a playschool not far from our home. I walked down with Radhika. My mother came with me for support. I thought I would chat with the principal, she would see Radhika for herself and there would be no question of not admitting her. There was a lump in my throat as I explained the situation. The lady was unmoved. No, she could not help us — it would create problems for her with other parents and with her staff. There was nothing more to say. I felt I had been physically beaten. I clung to my mother and wept. Was this going to be the pattern of our lives — rejection, ignorance, fear, inability or lack of desire to help? It was the second rejection we had suffered and it was excruciatingly painful. It still brings a lump to my throat and tears to my eyes. Do we pay twice over for what is no fault of ours? Was it not enough to have a child with a disability and know all that pain? Must we suffer rejection from society as well?

Next we contacted Dina Guha and made an appointment to see her. This meeting was going to change the course of our lives. Dina was a special educator, trained and experienced in the United States, and was until recently the Principal of the Sophia College Special School.

Most parents, unable or unwilling to do more themselves, were sending their children to this and other schools for baby-sitting services. The staff struggled to teach them, but during the holidays the parents did not work with their children. Dina found that they had reverted or regressed, and the school had to start the struggle from scratch. Now she was

only prepared to take on those children at her home whose families were willing to cooperate fully. First, both parents would have to pay to attend a two-week evening course which would run daily for three hours. Only then would she start a playgroup for their children. Mothers would have to attend the playgroup once a week, and maids looking after the child at home would have to spend another morning a week, learning from Dina how to manage the child.

Dina sounded knowledgeable and competent, and we decided to take advantage of this opportunity. There was absolutely no question of Ramesh not wanting to attend, or finding excuses not to attend. We both knew we must join, and we did. There were three sets of parents, three little girls; one had microcephaly, one brain damage and ours Down's Syndrome. In the event the parents of the child who was microcephalic decided not to attend the course, and were, therefore, also unable to send their daughter to the playgroup. Unfortunately they felt it was too expensive and weren't convinced of the necessity to learn themselves.

The course was going to cost a thousand rupees per family, and the schooling, five hundred per month per child. When one set of parents opted out, the remaining two decided to cover the shortfall, so that Dina got the minimum fifteen hundred rupees per month that she needed. Dina gave us prepared notes on child development, growth and behaviour patterns, and on the medical problems our children could face.

The course was extremely useful and stimulating. We learnt not only about our children with disability, but about our 'normal' ones as well — their moods, tantrums, developmental phases. We realised, too, just how important it was to have the complete and knowledgeable involvement of everyone in the home. At the end of the course Dina began the playgroup for Rianne and Radhika.

Chapter Three

Dina not only possessed the skills and infinite patience, but more than that she was an inspired and dedicated teacher. She was purposeful and demanding as well as warm and sympathetic. She was Radhika's educator, speech therapist, physio-therapist and developmental therapist rolled into one. As well as being our adviser on Radhika, she was our hope and inspiration. Once every week she paid us a home visit. She would observe family dynamics, help sort out any difficulties, guide us in improving our handling of the children, and show us all how to teach and play with Radhika, so that gradually we were able to use the same techniques at home as she did in her playschool. Radhika therefore got fewer and fewer contradictory instructions which was a great help to her progress.

Dina showed Sandhya and Aarti how to teach Radhika to play 'follow-the-leader', 'catch', 'throw-and-kick-a-ball', go down the stairs with alternating feet, climb the monkey bar and hang from it, walk along a narrow brick path while keeping her balance, jump, skip and hop. The girls thought this was great fun and thoroughly enjoyed teaching their little sister. These activities encouraged the learning of gross motor skills, as well as increased body image and balance. Dina also discussed and advised on good eating habits and supervised meals, and taught self-care skills like independent toileting, bathing, dressing, and putting on socks and shoes. It would have been easier and quicker just to do all this for Radhika

ourselves, but the aim was to make her self-sufficient and independent. She was slow, maddeningly so at times, but we always had to encourage her and be patient ourselves.

Dina's nursery school was equipped with a rope ladder, wheelbarrow, a tyre on castors, a sand pit, small musical instruments, a doll's house, books and art materials and a host of other simple but necessary equipment. The two girls had a short attention span and while one was hyperactive, the other was hypoactive. Often they were lazy or obstinate or both. Dina worked with tremendous energy and patience, firm but always cheerfully encouraging. Not wanting to try was due to fear of failure, she maintained. 'Can do' was her password. 'Radhika can do', and then Dina painstakingly showed her how, step by step, she 'could do', thus building her confidence and self-esteem. Today her words ring in my ears as clearly as they did all those years ago.

We, too, learnt how to break every activity into simple single steps, teaching her one step at a time, repeating it again and again until learnt, then moving on to the next. Persuading, encouraging and rewarding; on and on, every day, day after day. Dina was the force and motivation, and Radhika's slowly acquired skills were our reward. Dina's insistence on involving the whole family, the entire household, made the burden lighter for each of us.

Every evening Radhika would go down into the garden with her sisters to play with a group of children from the apartment building. Often she would sit on the sidelines and watch, partly unsure of herself, partly lazy. She would need to be coaxed and cajoled, and then she would join in actively, everyone helping her, everyone enjoying showing her how. She was lovable and friendly, hence much fussed over by all her sisters' friends — fortunate for her and us that she was a part of that young group whose parents did not mind Radhika's inclusion. We spoke openly about her disability,

and treated her as normally as we could. She was being trained to fit into family and society, and we encountered no hesitation, let alone rejection from neighbours or friends. I realise that this was rather unusual then, and perhaps even now, many years later. Did our own open, normal behaviour help in this general acceptance? I think it had a lot to do with it. Sandhya and Aarti were not embarrassed by her as her personal development and social skills were, on the whole, adequate and acceptable.

However Radhika was not yet dry at night. She was over three. Dina advised us to stop putting her into nightly nappies and plastic panties. She felt this would become a habit and not be easy to break. We had to potty her before putting her to bed, telling her firmly she should not wet her bed. If she did wet her pyjamas, she would wake up and I should then reinforce the potty bit. We had a few nights of bed wetting and then never again.

Children with Down's get into 'ruts' very easily. It is important to get them into acceptable 'ruts' or habits from the start. This, too, we learnt from Dina. Radhika was taught to brush her teeth, and do this everyday after breakfast and dinner. She never forgets. She used to kiss everyone 'goodnight' — family as well as friends. Dina advised against this, as it would become a habit she would neither be able to change later when kissing would not be appropriate, nor be able to discriminate between whom she could and whom she should not kiss. We should therefore get her into those habits that would be good and appropriate for her as a grown-up woman. Dina was a blessing. We had used Hindi in the early years with Sandhya and Aarti, and switched to English later when they began attending English-medium nursery schools. We began the same way with Radhika. However Dina felt Radhika would have difficulty learning two languages and that she would have only a limited vocabulary. Therefore we

should choose for her the language we used most in the family. Since this was English, we decided to speak to her only in English. She already had a fairly large vocabulary in Hindi and we were anxious about the changeover. We kept a notebook in which we wrote all the old words she relearnt in English and all the new words. Sandhya and Aarti kept track and taught her. The list grew and grew, and we finally gave up keeping track or being anxious when from about thirty words she had more than doubled her vocabulary.

Rereading all Dina's assessments, I relive all the effort that went into her early training. Dina discovered early on and recorded a great desire and zest in Radhika to do things herself. This encouraged both Dina and us, and Radhika's progress was quite remarkable. However, gross motor skills, body image and balance came quicker than fine motor skills. Her vocabulary increased by leaps and bounds, her perceptual skills slowly but surely, though conceptual skills came very slowly. Self-care skills improved — considerably. She was attempting to wash herself after toileting, and washed and dried her hands carefully and well.

Dina encouraged both her students to paint. Radhika did not like to get her hands messed up, but Dina was able to show her how to get them clean again. They hand-printed, finger-painted, used large sweeping brush strokes from left to right, up and down and round and round. Each movement and direction and colour was named again and again. Radhika began to enjoy this activity and we still have some of her earliest pictures. They tore and rolled and stuck coloured paper balls, thus developing palmar and pincer control and producing pictures as well. Since encouragement and praise were so necessary, everything she did was displayed on a board in her room. Each specific skill and concept was taught purposefully and with patience and joy. For instance, blowing bubbles, and drinking from a straw, helped breath control and

articulation. The preparation for reading and writing skills was also practised until learned and internalized. As her experience with new and 'formidable' activities grew, so Radhika's willingness to try increased. When she tried, she found she could succeed and success led to confidence, a greater interest and more self-motivation.

Dina, in her report on Radhika in November 1975, found her "always willing to try" but "withdrawn when frustrated," able to "separate from parents after explanation" and "perseverating with her success experience less than she had six months earlier." To persevere means to repeat an action for an excessively long time. Dina explained that children with disabilities continually repeated an activity they were successful at, not wanting to move to another for fear of failure. However, by December 1976, she had made "remarkable progress, her personality had blossomed, she was very alive to her environment which was no longer threatening and she shared a very healthy and accepting relationship with her family members."

At three and a half, the objectives for Radhika's training were to develop a positive personality and the competencies of a three-year-old child. She had to be disciplined appropriately in her reactions to family, adults, peers and younger children. She needed to be reinforced in her eating and other self-care habits and to distinguish acceptable from unacceptable behaviour. We had to help her develop her body image and confidence in moving around so that she would be less afraid and more secure in handling herself in relation to space, objects and balance.

Radhika was taught to follow simple instructions. At first one command, then gradually two and three. She learnt to pour water into glasses and carry a few plates at a time. She was extremely careful and hardly ever spilled water or dropped a plate.

Radhika made good progress in her one and a half years at Dina's nursery. This was continually reinforced at home. It was therapeutic for me too. There was so much to concentrate on and the rewards were there to see. Earlier misgivings about not knowing what to do just melted away. On this front it was a period of calm and healing.

On the medical front, though, we learnt from Dina more about all the areas we would have to look after especially carefully. Apart from hypotonia, children with Down's have weak air passages and get bronchitis easily. Playing in water and swimming were excellent, but we had to guard against chills. Exposure to too much sunlight was harmful. To quote Dina in full: "Physiologically, this child is like an unfinished human being. A tendency to catch colds, weak tonsils and adenoids, weak digestion, slow metabolism, delicate skin, poor circulation, poor dentition, thick tongue, high palate, malformation of bones, underdeveloped tear ducts and a tendency to myopia. They go through a long babyhood, hardly much childhood and age rather quickly."

This formidable list hung like a pall over me. I had read somewhere that they were prone to diseases of the blood, particularly leukaemia. This slack muscle tone, high palate and thicker tongue made soft foods easier to eat. Radhika moved them around in her mouth, chewed a little and was able to swallow them fairly easily. Dina got her to chew fresh carrots and apples every day as these were good for her gums and teeth.

In 1976, at the age of four, she had two acute attacks of tonsillitis and recurrent attacks of diarrhoea. We needed a blood test, and I took her to the Breach Candy pathology department. She was apprehensive. No amount of preparation made any difference. When our turn came, I took her in and sat her on the bed. She was terribly afraid. I tried to explain how it would not hurt, she would hardly feel it and

it would take just a second. The male technician got his syringe ready. He offered no word of encouragement or understanding. Her fear and panic increased. She would not let him come near her. She began to scream and kick and fling her arms about. He threatened, "I shall send your mother out of the room if you don't cooperate." This increased her panic and shock, and mine. No amount of comforting words from me helped allay her fear. Finally he called in another male attendant to hold her down and told me to leave the room. I did, and the blood was forcibly taken while she shrieked and screamed.

I was stunned by this experience and Radhika shocked by the harsh treatment and the use of force. Surely there must be a better way to deal with children's fears? No one had ever threatened her before. Radhika's fear was now compounded with distrust and shock. I hated myself for allowing the child to have an experience which has left her distrustful and fearful of all doctors, hospitals, tests and injections.

She cannot bear the fear of pain, let alone the pain itself. Sometimes I feel she has a sixth sense about medical interference with her system not being safe for her. I have developed a similar fear about myself. I have never liked to be poked or prodded, and do not like to put her through anything that is not essential. However when medical assistance is necessary, Radhika does not understand, nor is she troubled, for example, by the thought of teeth rotting and causing more pain than a simple extraction. I have learnt to respect her wishes most times but wish she was easier to convince when medical attention is necessary. This has been an added burden on top of trying to remember, all the time, all the things we must do, and all that we must not do.

Dina had warned us early on how Radhika would mimic gestures, words, looks, behaviour, etc, and that therefore we should all be careful with ours, since she would parrot with-

out discrimination. In each case we have found Dina correct and wise. On the one hand, knowing this has meant a greater burden of responsibility to follow the rules, but on the other, the results Radhika has achieved have been compensation enough. I remember my father's letter to me on my eighteenth birthday, telling me we have to work hard and pay a price for everything we want. We don't get something for nothing. How true, but what a hard way to learn this lesson!

In many respects we were a close, happy, normal family. Radhika's presence was a challenging and cementing one, involving all of us in her upbringing. The relentless struggle to make Radhika's an independent and valuable life gave the family a very real joint purpose and direction. We were in the struggle together, sharing the difficulties, the successes and the joys of her personality as it began to flower. Although Ramesh's job was demanding, he too made it a point to spend time with his daughters. The girls were unaware of the underlying heartache caused to us by Radhika's condition although, for me particularly, it was ever present.

Chapter Four

After five years in Bombay, Ramesh was transferred to Delhi. This was our first move after Radhika was born. She was four and a half then. We were fearful about losing Dina. We had long talks with her, discussing in detail the programme and progress thus far, and how we should continue and with whom. Dina gave us a written programme for the next six months and suggested we find a congenial nursery for 'normal' kids, as this would be a good exposure, and perhaps the only time that Radhika would find herself in a normal situation. We packed and left the city that had changed our lives forever.

In Delhi we found a pleasant little nursery school, not far from our new home in Vasant Vihar. The Principal, Cherry Misra, was amenable to having her. They had never had a child with a disability in their school before, but she was open-minded and willing to try it out. I had gone to her full of the fear of another rejection.

Radhika enjoyed going to school. She would wave a cheerful goodbye to me and three hours later she would come home, again full of cheer. The staff found her 'easy to deal with' in most respects, and were sensitive enough to see that the approach to her would have to be basically different from their approach to other children. She got on well with both children and teachers, involving herself in various activities, particularly enjoying singing, art work, recitation of nursery rhymes and playing 'teacher'. She had an adequate and grow-

ing vocabulary and understanding of the world around her. "She learnt more from individual teaching, was easy, friendly, happy, neither shy nor aggressive, and not a problem to have at the school." In fact her behaviour and participation was so normal as "not to be noticed even by parents who spent much time in the school," said the reports on her in this period. Cherry found that Radhika never needed to be scolded and was generally cooperative. Occasionally she would not like to leave an activity which she was enjoying — shades of the earlier perseveration. Cherry was extremely perceptive in her evaluation of Radhika, reporting that "it was necessary to be firm, but always gentle with her."

We kept in close touch with the school, and Cherry took an interest in knowing more about Radhika. Radhika invited her home for tea one evening and Cherry was surprised to find how talkative she was at home. The report from school indicated that "she spoke little in school unless specifically spoken to or asked a specific question. However, she communicated her needs and desires quite adequately." Cherry Misra felt that Radhika's "positive and happy home life contributed to her well-being and progress in school."

While Radhika was happy and busy in Cherry's school, Shishu Vun, her life at home was now without her sisters. Considering Ramesh's transferable job and the increasing difficulty in getting school admissions, we had decided to send Sandhya and Aarti to Ramesh's old boarding school in the Simla Hills, Lawrence School, Sanawar, in February 1978. Their departure left a void in our home and in our life as a family. For Radhika the separation was particularly hard.

However, from Delhi, Sanawar was less than a day's drive and we did visit them every six to eight weeks. Radhika was terribly excited each time we were leaving for Sanawar. She spent all the time she could with Sandhya and Aarti and their friends. Everyone loved her chatter and fought over whom

she would share a bed with, and who would bathe and help her dress the next morning. She was spontaneous and uninhibited, and fun to be with. She had endearing ways and responded to all the love, cuddling and chatter with gusto. It was heartwarming to see how loved and sought after she was. It must have been so good for her 'little' ego too! Her disability seemed to be no barrier whatsoever, either to her, or to her sisters and their friends.

Dina had explained how underdeveloped Radhika's self-image and ego were. This was usual in children with a disability. Her ego must be nurtured by us, she had said, and built step by step on success-experiences so that she developed it steadily. However, since it would always remain fragile we would always have to be gentle, reassuring and encouraging. This was the first time we had to look at ego as a valuable and essential asset without which there was no self-motivation. Therefore we had to motivate her on every front for many years.

To give Radhika something to look after in the home, and to provide something for her to do, we decided to keep a pet. This was when Pilla the pup forced himself into our lives through the bars of the front gate.

For three days he was picked up several times and put outside without food or water, but eventually his persistence paid off and we succumbed. He was cleaned and fed but not allowed inside the house. One night, Ramesh heard him barking frantically. Next morning, we discovered various signs of an attempted break in, prevented by Pilla! It was agreed that he was a hero and must become a part of the family and be allowed indoors.

Radhika enjoyed having a pet and would occasionally feed brush him. Having a pet was a good idea. Here was something to love and look after. New words were introduced into her vocabulary and her experience was enlarged. Sadly, Pilla got

run over by a speeding truck. Radhika was most distressed; again and again she wanted to know how it had happened, and expressed her shock and grief in words. She even wanted to see the body. However we were able to avoid this by telling her that the servant had already picked him up from the road and buried him in the ground. She spoke of his accident and the bad truck driver who ran over Pilla, for several years after.

Radhika has always had a gentle, caring nature. Despite her own timidity, she feels sympathy for other people's illness or injury. Her caring instinct is aroused immediately. She will not only express her concern in words, she will console and comfort. She is also very sensitive to people who are sad or depressed, often being the first to notice this and bring it to my attention at once. To be able to give love and care seems to make her feel good about herself too.

Since these children learn better from actual experience, it was necessary and important to give Radhika a wide range of experiences. Her memory has been one of her strong points. She doesn't forget what she has seen, done, heard or taken part in. Perhaps to compensate for her inability with the three R'S, (Reading, Writing and Arithmetic) we went out of our way to see that she got as varied a range of experiences as possible.

In Delhi we continued to follow Dina's programme. Plenty of activities to increase gross motor skills — tricycling, scootering, roller-skating, skipping, balancing, jumping, pushing, pulling, running, throwing, catching ball and ring, and paddling in the swimming pool. The fine motor skills were being taught in the nursery school. We continued to match and sort cards, counters, coins at home. We read stories together, played ludo and carrom and of course took her on all our trips outside Delhi. She was fairly proficient in bathing and dressing herself by now, and had almost learnt to wash her hair and brush and comb it.

We were fortunate in still having the same maid who had learnt from Dina how to handle and teach Radhika. Celina not only loved Radhika, but was very good with her. She was a friend and companion and knew just how to jog her on. Radhika was nearly five years old when we first moved to Delhi, and though she was happy and actively involved in Shishu Vun, we and the school felt that she needed extra and individual help in certain areas of learning, particularly reading, writing and the ability to understand concepts.

After scouting around, we were introduced to Meena, who had experience in teaching. We met, and discussed Radhika's slowness with recognition and writing of the alphabet and numbers. Meena agreed to give her private lessons. We were also struggling with Radhika's colour concepts; it was proving very difficult and I thought she might never get it right, but referring back to Dina's notes, we persevered. Suddenly one fine day the reds, yellows, greens, blues, blacks and whites fell into place and we progressed to VIBGYOR. In Shishu Vun they were singing a song about VIBGYOR, and this kind of reinforcement was just what Radhika needed all the time.

In September 1978, when Radhika was six and a half years old, Ramesh was transferred again, this time to Calcutta. Moving is always hard and finding suitable arrangements for Radhika difficult. This time we were also moving further away from Sanawar and Radhika's sisters. We had the same worries about Radhika — where to school her, who would help with special education, how would she adjust? This time there would be no sisters to help ease the whole process. Celina, our dear colleague in raising Radhika thus far, decided to leave our employment. All in all, we felt this was going to be the hardest move we had made so far.

I have found that my fears, however normal, lead me to seek advice and help from whatever sources I can find. We had known Ranjana for a few years now. She had worked in

the Okhla school with Afzal Friese and then worked privately. In fact, she was leaving Delhi herself to attend a course offered by the Spastics Society in Bombay. She knew Calcutta well, and when she heard we were to live in Alipore suggested we try the Tiny Tot's School. She also gave us an introduction to Purobie Bose, who worked in the Calcutta school for spastic children and would be a good person to advise us.

We arrived in Calcutta at the end of September 1978. As soon as we could, we arranged to visit the school for spastic children. We wanted advice on the best and most suitable place for Radhika. But no, they had no place for the mentally disabled, and no, Purobie had no time to meet us. This was an unexpectedly unhelpful attitude and filled us with alarm. However, we were able to contact Purobie at home. She offered to meet us at once and see what she could do.

Purobie was very busy at the Spastics School, but agreed to give Radhika private lessons twice a week for an hour each time. This was a great relief. Meanwhile, I took Radhika to the Tiny Tot's nursery. Mrs Sapru read the reports from Shishu Vun, Delhi and agreed to let Radhika join her school straightaway. I am sure Cherry Misra's report, that it had been no problem having Radhika, influenced Mrs Sapru positively.

I would walk her down to school each day, telling her about the rules of the road, how she must wait, look left and right and left again, before crossing. It was a busy road and though she would never go to school alone, we did need to begin teaching her road safety rules.

She was quiet at first, but as usual learnt to relax with time and familiarity. She enjoyed going to school and participating in and learning various things. She made an attempt to make friends, enjoyed 'singing and actions', was 'very neat and tidy in her habits', but 'wasn't conversing much in school'. They found her oral work very good, spoken English also very good, and on some days, she was 'very bright and showed

remarkable intelligence.'

Radhika spent a year in this school, the last two terms in upper nursery. Her comprehension and interest gradually increased, but she had her bright days and her dull days. Her reading and writing were poor, but number work was good. She continued to enjoy painting and music particularly, and in the end-of-term concerts she was invariably given a small, if silent part.

Purobie concentrated on reading, writing and counting skills. Special cards were made so that Radhika could read and write about herself, her activities, friends, sisters, home. Jane and Peter from the Ladybird books did not have the same appeal, as they were unrelated to her own life and experience. Radhika developed a great relationship with Purobie who was full of fun. She was also young, energetic and enthusiastic. Her daughter became a friend too and sometimes visited and stayed for the night. She was only very little and Radhika's caring instincts were aroused and satisfied with looking after Joeyta.

Our home was without Sandhya and Aarti, but in the large compound there were several blocks of flats, and many young children used to gather in the evenings for playing in the garden. We had found a nice young girl to work for us who was bright and cheerful and soon learnt to handle Radhika well. Meera would take Radhika down in the evenings and play with her on the swing, but she didn't know how to organize group games. Though the children were friendly, no one quite knew how to break the ice. This is where I had to intervene and teach them, particularly Meera and Radhika, to play with the others games like 'London', 'I sent a letter', 'Is the lamb at home?', 'Hide and seek', 'Catching cook', running and skipping races, catching and kicking balls with the others. Once I had shown them how, and played with them several times, they had a wonderful time together and

without me.

It was Sandhya and Aarti who wanted us to live in a block of flats, so that Radhika (and they, when they came on holidays) would have company and friends more readily than if we were in an independent house. It was the right decision. Radhika's young friends would often come to the flat to have a drink or play with her toys, and sometimes they would take Radhika over to their homes. They were a lively bunch, sometimes quarrelling, sometimes teasing, but generally well-meaning and friendly. Whenever I felt energetic enough, I would get them together and we would act out familiar stories. This was thoroughly enjoyed by everyone.

It is true that the other mothers did not need to 'organize' games for their children. They could play on their own. This was the difference between them and Radhika, but they all got a lot out of the things I organized, and of course I organized them so that Radhika could learn and enjoy herself as she went along. She did need extra help to make both her play and her friendships worthwhile, and I knew I had to do this for her. It was fun for me too, and I had the energy then.

Sandhya and Aarti would take the school party home on the Sealdah Express twice a year, in June and December. Radhika expressed great excitement as the day of arrival neared. She would help get their room ready and shop for their favourite things. At last they would arrive, dusty and bedraggled but very happy to be home. Radhika never left their side. She was always with them, very talkative and attentive to all their games and stories.

In our two years in Calcutta, she saw them only four times. Had she not had a good group of friends, she would have been extremely lonely and bored, or else I would have had to do much more to see that she wasn't.

After eighteen months in Tiny Tots, when Radhika was seven and a half years old, we found that the school was

unable to give the kind and extent of individual attention she required. Her physical size too began to be noticeable among the smaller children. As yet there was no English-medium special school we could transfer her to. Purobie had got us involved in setting one up in the future, but at present the choice was limited. After careful consideration, we decided that a change would be good and moved her to the Higgins School not far from us. Higgins went further than Tiny Tots, and although Radhika would be in the upper infants group at nearly eight, at least the school had other eight-year-olds, so Radhika wouldn't stand out as much, we hoped.

We were, and always have been, very conscious that Radhika's self-confidence should not suffer. Dina was responsible for showing us how important and how motivating self-confidence is, and that when she had it, she definitely did better. At Higgins, her acquired skills were judged to be 'B' grade except for reading and writing, which were 'C' grade. In natural aptitudes, they found the same interest in art, music and singing as had been found by others previously. The teachers' general comment was that "Radhika was a very sweet and helpful child, able to produce good work given individual attention." This was in 1981 when Radhika was nine years old.

From the very start of her education Radhika has benefited most from individual teaching. In fact we had to firmly persuade her to look at the person she was talking with, make eye contact and not roll her eyes upwards or sideways. We have also had to remind her constantly to keep her mouth shut when she is not speaking, to swallow saliva rather than drool, to avoid clicking her tongue at least during her waking hours.

What Dina taught us to do with her required endless patience and gentle but firm handling. That she was acceptable and accomplished according to her age in areas of general

awareness, if not in specific academic skills, was something of a reward for our efforts. We could hardly believe this was the same child who could not be expected to walk, eat, dress and talk. Obviously Dina's method, tried and tested, had been confirmed by the success of the struggle with Radhika.

Now nine years old, Radhika was with normal children half her age and looked much bigger than her classmates. She was not, however, being promoted with them at the end of the academic year. The three and a half years in normal nurseries had been useful in providing her a degree of exposure to a normal school situation, without so far showing up her shortcomings. It had been a brief respite for us to have her in a 'normal' nursery. We could tell acquaintances where our girls studied without having to explain. If anyone showed further interest, we always told them she was mentally disabled and never felt any shame in saying so.

However, we were certain about one thing — that we must always put Radhika first. She would have lost confidence if she had had to see herself being 'left behind'. We had accepted her limited capacities and did not think it wise to keep her at the normal school, either falling behind, or struggling too hard to keep abreast. Learning at the normal pace would have put too much unnecessary strain on her, and her happy confident nature would have given way, we were sure, to tantrums, loss of self-esteem and finally to all kinds of behavioral problems. Instead, having come to terms with her academic slowness, we wanted to ensure she learnt what she could, at her own pace, so that she remained content, at peace with herself, proud of what she did achieve, and not unduly mindful of what was not possible for her. Fortunately Purobie's new school was ready to open, and we gratefully moved Radhika out of Higgins.

Meanwhile Radhika was developing sure signs of increasing self-interest. She had extremely winning ways and was,

most times, easy-going, pleasant, cheerful and placid. She was however, learning to use her charms to get her own way. We were happy she knew this much, but had to watch against giving in and spoiling her. For instance, she would ask for something to eat or drink from one person; if refused, she would make her way to another, not so strict as a family member or the maid and thus often succeeded in getting what she wanted.

We also had to safeguard her from danger. On one occasion she showed considerable initiative. We had a house rule that Radhika must stay home and rest in the afternoon after lunch. But one afternoon, when her grandmother was taking a nap, she managed to drag a chair to the front door, clamber on to it to get to the bolt on top, and was discovered stretched against the door trying to get the bolt down. We were delighted by her initiative, but realized that she could now walk out whenever she chose. Safety had to be taught to her quickly; safety on the roads, safety against strangers and intruders. These sorts of concepts are hard to teach. Strangers are strangers in varying degrees and not all are suspect. How should we teach her to distinguish between them? Since she learnt best from actual experience, we allowed her to 'experience' as much as possible. She did acquire some skill in discrimination, but not enough for her safety, at any rate not enough to assure us of her safety; she needed some degree of supervision all the time.

Radhika has an essentially simple and trusting nature. She has been more protected from the slings and arrows of the big wide world than other children. Always accompanied by a loving adult, she had not faced any serious or dangerous situation on her own. Her nature and experience would encourage her to believe that the world is full of good people and that she cannot come to any harm. We only wish this were so. However, we know there are people who would take

advantage of her innocence and lack of suspicion. But the problem has been to make her more worldly-wise; how to show her what she should be wary of and how best to protect herself? This has been a worry. We have had to take each day as it comes, pointing out the pitfalls as they become evident, drawing lessons and comparisons from as many events and situations as we have been able to.

Chapter Five

Ever so often we have needed a break and been fortunate to take one. My mother was always ready to look after the girls, either in our home or hers. In fact, each one of them has had quite a remarkable relationship with her, thanks to her wisdom and her fun-loving ways.

However, we had never before left Radhika with friends. So far no friends had offered and we had had no need to ask. In 1981, when Radhika was nine, Ramesh had to visit Colombo on a bank inspection and wanted me to go along as well. Our friends, the Javeris, said they would love to have Radhika stay with them and that I should go ahead and accompany Ramesh. It was a wonderful offer, and though we wondered how Radhika would take our going away and leaving her behind with them, we decided to give it a try. I could always get back earlier if it became necessary. Nani and Shirin Javeri loved Radhika, and their only child, Laila, was about the same age. Moreover, Radhika was very fond of them herself. We could tell she was nervous, but we reassured her and took her across to them the day we were leaving.

We rang from Colombo every four or five days. She sounded a bit wistful but well and happy. The Javeris assured us all was going well and they were still enjoying having her so we could proceed to enjoy our holiday and we did. It was a relief to be free of all our day-to-day concerns for Radhika, and to be on our own, and there had been no need to hurry back early either.

Radhika was, however, delighted to have us back and we returned thoroughly rejuvenated and ready to start afresh. She said she had had a happy time despite the occasional fights with Laila. The separation had been good for us all, and it had been possible only because of the Javeris' spontaneous and genuine offer to have Radhika while we were away.

I wish all parents could have regular breaks from their children, and especially from their children with a disability. This is one tangible way in which family and friends can help to ease the strain. The child benefits from a physical separation and learns to adapt to other people and different routines, and parents can recoup their energies.

Sometime after our return from Colombo we noticed that Radhika's toes were turning outwards slightly. She was flat-footed, and this was now an added complication. Dina had showed us exercises to strengthen her feet muscles which we had been doing with her off and on but we needed to investigate this new aspect.

On our next trip to Bombay, we asked Bansri for her advice. She sent us to a leading orthopaedic surgeon. He took a look at Radhika's feet and asked her if they hurt when she walked. He looked surprised to hear her answer at all, and told us that we could have cosmetic surgery done when she was about fifteen years old; until then we should give her broad-toed shoes. I asked him what he would do if she were his daughter. He looked discomfited and was silent for a while, finally saying that he would wait.

After the appointment we went to visit Dina who lived in the same building. When we told her where we had been and what had transpired, she laughed sadly. The man had a Down's daughter himself and had kept her shut away all these years; ironic that without knowing this I had asked him such a loaded question. I would have thought he would have been

enlightened, seeking to do better, setting an example. Instead, he could not face it and chose to keep his own child hidden away. He must have realized how accomplished Radhika was by comparison, thanks to all the efforts made on her behalf.

Radhika was now over ten, and showing signs of vanity; she wanted to wear the shoes that were in fashion — pointed toes and small heels. We had to be firm and buy her chappals or broader-toed shoes. These were not easily available, fashion and comfort seldom going hand in hand. For Radhika broader shoes with built-up arches were essential. We had to make do with the best that was available.

In this period Radhika suffered numerous bouts of tonsillitis. She was treated homoeopathically, but finally Dr Dadina, the paediatrician, advised we get her tonsils removed. The top ENT man absolutely refused to operate on her when he heard she was a child with mongolism. He had lost such a child on the operating table, he said, and would not take the risk again. So we had to look for another ENT surgeon. We found a younger man who wanted a clearance on her heart and lungs from a paediatrician he recommended.

An appointment was fixed. Since it was a mere checkup it was easier to convince her about going to the doctor. He had a cursory look at her and decided that because she had Down's Syndrome she must be a 'cabbage'. He tried lifting her onto his examination table without an explanation. She kicked and screamed and fought. He looked uncomfortable and distinctly puzzled, and had to exercise his charm to conduct the rest of the examination. "Heart and lungs are fine", he said, "but is she mongol?" Had we had a chromosomal study done? He could not believe that a child so vocal and 'all there' could be retarded.

The surgeon was now prepared to operate. We talked to Radhika plainly and in detail about what would happen and why her tonsils had to be removed. The promise of lots of

ice-creams after the operation made it easier for her to co-operate this time. However, we insisted that her paediatrician be present. Our fears were justified, especially as what should have taken half an hour took over two hours. We paced outside wondering what was happening. Then a nurse told us it would not be much longer. Finally she was wheeled out, and the paediatrician came to the room. She said, "You must never say Radhika has 'Down's Syndrome'; doctors don't know what that is. Always say she is Mongoloid." The anaesthetist evidently did not know what Down's Syndrome meant, nor had he bothered to find out before the operation. When he began anaesthetizing Radhika, she began to collapse. Thank heavens we had insisted on Dr Dadina's presence; she saved Radhika by prompt oxygenation.

As was explained to us afterwards, Radhika had had to be kept well oxygenated; there were two types of anaesthetics which should never be used on her. So many years later, my hair still stands on end to recall the ignorance and callousness of 'good' doctors and anaesthetists.

This experience confirmed my faith in homeopathy, especially for Radhika, and whenever possible our first resort has been to homoeopathy. The homoeopathic physician looks at the whole case, listens carefully and values every detail he is given. Most times his medicines have worked well and without side effects. However, it isn't always possible to reach a homoeopath, and in cases where surgery is required there has been no alternative.

I myself have had an inordinate fear of injections ever since a childhood illness requiring sixty injections round the clock at three hourly intervals. And uncannily enough, Radhika has not only sensed my fear but has been deeply influenced by it. She is just as fearful and suspicious but infinitely more uncooperative. So even a regular visit to a dentist becomes a major exercise for all of us.

Dina had warned us about all the dental problems Down's children have and unfortunately this was confirmed in Radhika's case by one fairly successful visit to a dentist when she was nine. The X-rays and examination revealed that "her baby teeth, late in appearing, were late in falling out and that two baby teeth had no successors at all. One baby tooth had been retained and should be extracted, to allow the permanent successor to erupt properly. The upper permanent central incisors were rotated and in 'cross bite', treatment for this should be undertaken at a later date." It meant she would have to visit a dentist regularly and we would have to help her overcome her unwillingness and fear each time.

By the end of 1980, Radhika had spent time in two normal nurseries and one special school. Purobie's final report stated that Radhika's language skills were good. "She comprehends simple questions and gives simple answers, relates experiences in a fairly coherent way, obeys simple instructions, can execute a triple order (this, then, afterwards), repeats a simple story." It must be noted that she was ten years old, and the emphasis was on 'simple'.

The report also stated that her "writing skills were improving but she needed a lot more work on prewriting skills like stencilling, dot-to-dot joining, tracing, cutting and pasting. Visual perception and visuo-motor co-ordination was good". In reading, "her visual discrimination and scanning, recall and closure and sequencing memory were good. Auditory and tactile discrimination needed improving, as did her attention span and spatial awareness. Her body awareness was quite good." Furthermore, "her number work, shape, colour and size recognition was very good, as was sorting according to differences." However, she did not understand 'more' and 'less', 'one' and 'many', but could count mechanically to ten and recognize number symbols from one to ten. She 'plays at shopping', said the report.

In general, Purobie felt that Radhika had come a long way and was capable of doing "much more which would help her develop social, leisure and daily living skills." Purobie, like Dina before her, gave us a long list of daily household chores for Radhika to learn through practice, simple but necessary tasks that would help others and make her feel useful in the home. There was another long list of possible leisure activities — simple table games like Ludo, dominoes, Chinese checkers, painting, stencilling, puzzles, making a scrap book, watching TV and then discussing the programme. Everything had to be geared towards a slightly higher standard — enough to keep her motivated and progressing, and us as busy as ever!

Radhika had undoubtedly continued to make progress over the last two years, but the differences between her and her normal peers were showing more markedly now. We had been told that the gap between her physical age and her mental age would widen as she grew older. At three, she was found to be functioning at the level of a two and a half year old, so the gap then was only six months. With all our concentrated efforts, the gap now was more like four to five years. Yet there was no denying she had come a long way. She was functioning at different levels in different areas, and though her intellectual skills were way behind those of her peers, her social skills and use of language were much less so. Hence she required special educational inputs and normal socialization.

In Purobie's school and with peers in the compound at home, she was getting a fairly good mix. To know that the gap was inevitably widening, to recognize it and to work within it required acceptance and understanding on our part. We ourselves had made a great deal of progress and most times I felt good about it. Sometimes, however, her slowness was a sharp reminder of her intellectual disability. Perhaps I was not able to hide my disappointment very well. Radhika,

sensing my mood, would withdraw, looking downcast herself. This would shake me out of my depression, and then for a while we would be normal and natural again. She was extremely sensitive to my every mood, and seemed to desperately need my approval. She would often mimic my tone of voice, and repeat words I used, thus sounding strangely adult, which together with her small physical size, was quite funny to observe. There was a unique, as it were, bitter-sweetness to our relationship.

Chapter Six

In late 1981, we took the decision to accept a job based in Hong Kong. Fortunately Sandhya would soon complete her CBSE final examination, and Aarti her tenth. It was good timing, and they would benefit from a college education abroad. Leaving India, families and friends was hard. Yet this was a good opportunity and turned out very well for each of us.

Once again we were sorting, packing and saying farewell. Ramesh went to London for a few months and Radhika and I moved to Chandigarh to my parents' home. Sandhya and Aarti finished at Sanawar and in April we finally got together in Hong Kong. Saying goodbye to our parents was harder than we had imagined, but we were all excited at the prospect of living abroad.

Settling down in Hong Kong was quite difficult as Ramesh had a very demanding schedule. Aarti was so miserable that she wanted Sanawar to keep her a place for a few months while she made up her mind between Sanawar and the American school in Hong Kong. Sandhya wanted to go to college in the United States, but there was no time to appear for the entrance examinations and seek admission, so she was persuaded to get two A-levels in Hong Kong and then go to college the following year.

Aarti finally decided to join the American school, Sandhya the German-Swiss School, and Radhika was admitted to the Bradbury Junior School, part of the English Schools' Foun-

dation which provided education to the English-speaking children of the British colony. However, all schools were closed for the summer vacation. Hence until July, all three girls were at home with nowhere to go, and no friends. Each was miserable, and so was I.

One day, after Radhika had been in her room for a while, we found her at the front door, struggling with all her belongings stuffed into several plastic bags. "Where are you off to?" we asked. "I'm going home", was her answer. "But Radhika, this is our home now." "I want to go back to Calcutta." She didn't say she was missing the familiar life and friends in India, but she demonstrated it unequivocally. This was often her way.

It was never enough merely to feel for her. We had to rack our brains and come up with ideas that would be a positive help. The early loneliness and friendlessness in Hong Kong was heartbreaking. After much sharing of ideas, we decided to buy her a life-size doll, as realistic as possible, though we managed to find the right one only with some difficulty.

Radhika was befriended — it was a 'he' she said, and called him Blake, after her hero in 'Dynasty'. Blake was her constant companion. She would keep him with her in bed at night too. I think he was more than just a friend. We often saw her hug and kiss him, there was so much passion in this relationship. Studies on sex and marriage in people with mental disability had found that dolls often replaced humans, and that this was better than nothing. So we tried to treat her and Blake as normally as we could.

Mentally challenged children need more than usual attention and watching. Unfortunately we tend to overwatch them, giving them no time of their own in which to indulge their fantasies or even their natural curiosity. This has been a constant dilemma for me. There is a definite need to watch and supervise. Radhika had to learn not to overstep the limits

of acceptable behaviour. She also had to learn not to impose her will especially when younger children visited. Fine distinctions had to be made about what was acceptable, and with whom.

I realized that normal youngsters found the time and place and people to experiment with their developing feelings. I was torn about how much privacy we could safely let Radhika have; every time she took a friend off to her room, I would worry, and after a few moments had to 'go and see'. Sometimes she would shut the door to her room; this meant she knew that what she was doing was not quite acceptable. We tried to impress on her that physical closeness, like giving a hug or kiss, had to be mutually acceptable or else her friend would not like to visit her again.

Sandhya and Aarti had boy friends with whom they were close, sometimes exchanging a hug or a kiss in front of Radhika. This posed the problem of double standards for her and her sisters, so that we finally had to ask them to refrain from such things in her presence. This has been a major and complex area and one that baffles me to this day. I would like her to have a boy friend and even perhaps marry — she needs love and sex like all of us — and yet could she learn and be trusted to know what is permissible? And how does one explain all that needs to be explained? It is easier to say it's wrong, it's not for you — ban it. However, I believe it is natural and good and if it could be worked out, I would be happy for her to know the joys of intimate friendship, sex and yes, even marriage. At this time I was able to send for the relevant books from England, and found Greengross' *Entitled to Love* and *Sex and the Handicapped Child* particularly helpful.

If she had had a brother, Radhika might have had a more natural introduction to the opposite sex. Certainly it would have made it easier to explain about sex and acceptable

behaviour between girls and boys. For all the strength of our feelings, this was a delicate area, not easily shared with friends outside the immediate family. The very explicit TV programmes didn't help her or us. Through scenes of torrid kissing and lovemaking on the screen, she would hold her hands over her eyes but watch through separated fingers. The instinct was quite natural, but definitely exacerbated by TV. She was ten when we arrived in Hong Kong, eleven when her sexuality began to be noticed, twelve when her first period started, and fourteen by the time we left for Sydney. There was more to come as she developed.

In Hong Kong we stayed in a hotel for the first month or so. It was very grand with all its shining glass and brass, fancy shops, escalators and lifts. Radhika's eyes were popping out all the time. Nervous of the escalators at first, she'd soon learnt what to do and had great fun going up and down several times a day. And the TV set — what a draw that was! As soon as she woke up in the morning she would switch it on. That was the start of a TV addiction which was not without its negative points. It did, of course, increase her attention span, concentration and interest in a variety of programmes, but it certainly took a great hold on her. I dislike the box because it takes over one's life, but it was a friend and companion to us all in those lonely, early months. We sat glued to the daily dose of 'Dynasty' or 'Dallas', news, international sports and the films we chose to watch.

During our stay in the hotel, we found an unfurnished flat in Repulse Bay, an expatriate residential area in the south side of the Island. Furnishing it from scratch was a marathon task, entailing daily visits to dozens of shops over several months. On one such afternoon Ramesh joined us in the main shopping area of the Island to look for carpeting and furniture.

Central Hong Kong during lunch hour is a stream of moving humanity. When we thought Radhika was tired, we

sat her down in one shop and told her to wait there while we visited a carpet store across the road. Okay, she said, and off we went. It took us longer than anticipated. When we finally returned we found she wasn't there. The shop assistant said she had left a while ago. Imagine our panic. A little, mentally retarded girl of ten, lost in the crowded central Hong Kong streets of mainly Chinese-speaking people!

For two hours we fanned out to search for her, getting more desperate by the minute. No one had seen her and she was nowhere in the vicinity. Sandhya, Aarti and I went back to the hotel but she wasn't there either. We described her at the reception desk and asked them to keep her there if she turned up. Finally, Ramesh went to the nearest police station. They took the details and announced them on their walkie-talkie sets, so that all policemen in the area were looking for a little Indian girl in *salwar kameez*, ten years old, but short and small for her age, with two pony tails, who could speak and understand English. Ramesh waited at the police station while we waited at the carpet shop. Our hearts were in our mouths and dreadful thoughts of what could have happened raced through our minds.

She was found after nearly three hours. She had waited for us a while, then thought she would walk to the carpet shop where she thought we were. Instead of merely crossing the road she had walked along it and crossed a couple of busy, major streets. Finally, lost and bewildered, she went into another carpet shop (most are run by our subcontinentals) and told them she was lost. They made her sit down, gave her a coke and tried to find out her name and address. She said she was Radhika, daughter of Ramesh, no surname unfortunately, and that we lived in the Hilton Hotel. They didn't believe her. They asked for her telephone number. She remembered and gave them the Calcutta one! Since most Indians lived on the Kowloon side, they assumed it was a

Kowloon number, and rang it only to find a Chinese household. Finally, they rang the same police station and were told to bring her along as the father was waiting for her there. The police officer advised Ramesh that she must always have her identity on her and should never be left alone without it.

Relief, evident in his voice when he called to say she had at last been found, expressed itself in a long hard hug to her when she arrived at the police station looking overcome by fright. Poor little girl. It had been a traumatic experience for her, as it would have been for any normal ten-year-old. For us, knowing her handicap and cursing ourselves for not having anticipated such a mishap, it was a virtual nightmare.

Ramesh walked her from the police station down to the carpet shop where we were waiting. When she saw us she let go her father's hand and ran sobbing and shaking into my arms. What blessed relief to be reunited! We sat comforting her while she told us all that she had been through. The kind owners allowed us to recover over welcome cups of hot tea for us and cokes for the girls. We promised her this would never happen again because we would teach her what to do.

When we could look at it calmly we felt that on the whole and despite her disabilities, Radhika had handled the situation fairly well. She had not been knocked down nor had she gone too far. We began immediately to educate her about her full name, her father's full name, where he worked and where we lived; also the home and office telephone numbers. And last but not least, that she must never move from where she had been told to wait. "We will come back to you, so you just wait for us." It took several weeks but as with so much else she did learn.

Some time later, she got lost in a large department store, but found her way to the information desk and before long we heard her name being announced. She had recognized a

shop assistant and asked for help saying that she had been separated from her parents. This time she gave her full name and that of her father. No doubt simpler than being lost in central Hong Kong during the busy lunch hour, Hong Kong shops too can be intimidating if you don't know where and how to seek help. She had managed better because we had trained her carefully and pointed out the information counter as we passed it. It was the very first time that we had lived outside India; it was strange and difficult for us, let alone for Radhika.

Aarti made only one close Chinese friend from the American school and Radhika too made only one, Annson, whose family were American citizens doing business in Hong Kong. Ramesh and I tried meeting our Chinese neighbours, a paediatrician, but they consistently ignored our overtures. In all our four years we made no Chinese friends. Older Indian residents assured us this was quite normal in Hong Kong. However there was a sizable Indian and Pakistani population settled permanently in Hong Kong who spoke Cantonese and were better accepted than those of us on temporary postings.

That first summer before schools reopened we went to the beaches, wandered in the shopping complexes, gazed at multistorey car parks and the bright lights at night. We found Chinese food a great delight, but Radhika loved her familiar '*dal*' and '*chawal*' best. The first time we went to a Chinese restaurant she looked the menu over carefully and asked the waiter "*Dal hai?*" However it was not long before she too developed a taste for Chinese food and began to use chopsticks proficiently. Then '*dal chawal*' was accepted as home food only.

Chapter Seven

The Bradbury Junior School fortunately had a 'Special Education Unit'. It was a class for mentally challenged children with English as the medium of instruction. No other regular schools in Hong Kong had such a facility; the Chinese schools were only for the Cantonese-speaking local population. The educational psychologist the school asked us to meet wanted us to take Radhika to his clinic. I explained that he might better visit and assess Radhika in her own home where she would be more relaxed, which he accepted. He had read carefully through her educational and medical files and noticed that, although diagnosed as Down's Syndrome, this had not been confirmed by chromosomal investigation.

The educational psychologist found her 'friendly and responsive' from the moment he arrived at her home. "She chatted animatedly about her family, her room, and the move to Hong Kong. Her language was well developed and her speech intelligible. A few speech sounds were poorly pronounced and poor dentition made her physically unable to make a good 's' sound." He advised a hearing test as early as possible.

I would like to quote the report fully. "Intelligence testing, using the British Ability Scales, confirmed earlier assessments of Radhika performing as a child with limited intelligence. On tests of verbal reasoning, non-verbal reasoning, memory and spatial awareness, Radhika worked at around five to five and a half year level. On the Neale Analysis of Reading

Ability, Radhika read at a six year seven month level, with comprehension commensurately well developed. Radhika had been taught by the 'look and say' method, so when faced with an unfamiliar word, she was unable to analyse it phonetically. Her reading and spelling would improve with a slow but legible print.

"She counted concrete objects reliably to twelve and was able to compute simple addition and subtraction of units using blocks or counters. Her approach to number problems was fairly mechanical, having learnt the process by rote rather than by understanding.

"Radhika's self-help and social skills were well-developed. She could dress and undress herself; feed neatly and politely; take care of washing and toileting unaided; find her way around familiar buildings and follow classroom routine.

"The main educational objectives for Radhika must be to consolidate reading, writing and number skills — to further develop social and self-help skills, so that she could lead as independent an adult life as possible, e.g. understanding money, shopping and cooking skills, dress sense, following simple, written instructions, use of public transport, familiarity with common signs and notices, the social skills of asking for help and advice, simple letter writing, etc."

The report was fairly accurate in its assessment. It confirmed most of what we already knew, but it did give the special unit teachers a good insight into Radhika's level of functioning, and a guide to the areas which needed reinforcing. The school was given a copy for their reference.

I was pleased with the result. It was as if Radhika had 'made the grade.' Obviously we had been on the right track so far, even though we had not done the reading and number skills as well as we could have. Actually, until we got to Cromehurst School in Sydney, we didn't know just how much she was capable of learning, and so perhaps we chose the

simpler methods, thus inadvertently restricting her abilities, but when her social skills were noticed and commended by outsiders, I felt a particular pride. Radhika's acceptance, it seemed, depended on her social graces. To me this important aspect was of special relevance. I have put a lot of emphasis on this, and taken trouble to teach her not to drool, to shut her mouth when not speaking, look straight, make eye contact, walk gracefully, eat politely, to mention a few.

I was also pleased that 'we' had made the grade. Mr Bradley ended his report with, "Mr and Mrs Chand have a very good understanding of Radhika and her special needs. They will be a great resource, and will be able to consolidate Radhika's new skills." I felt complimented. The success of our hard work with Radhika had been acknowledged by an objective professional.

During 1982-83, she settled into the new environment of Hong Kong. We took her on all our trips within Hong Kong and outside. Each new experience was a little frightening and unnerving for her initially, but added to her knowledge about the world around her, her vocabulary, her subjects of conversation, and her self-confidence. For example, the ferry between Hong Kong and Kowloon meant finding the right change, getting tickets, going on board, finding seats, noticing signs, observing the water, the ships in the harbour, the pollution in the sea. She may have been content merely to follow and sit quietly, but we constantly engaged her attention, pointing out each detail we could and encouraging an interest in looking around, and being generally more aware.

She enjoyed going to school and within the first few days I was able to drop her there and come away at once. The special unit had approximately twenty children and two trained staff members. Learning skills were taught in the unit, but Radhika joined her peers in Primary 6, P6 for short, for physical exercise, activities, assembly and music. She enjoyed

music and was most responsive in the music lesson. She opted out of being on stage in a class assembly, and did not always participate in the physical exercises. However she attended gym club and enjoyed this out-of-school activity very much.

Her class teacher found she operated best in a 'one-to-one' situation, with another child or adult; in this situation "she communicated well and could elaborate on her personal experiences." In the larger group situation she was more reticent and would talk, although uneasily, only when she felt sufficiently encouraged to do so. At eleven years, they found she 'enjoyed being the centre of attraction.' Her teacher felt "she had much to give but lacks confidence to initiate discussions in large groups."

We decided, with her teacher, to maintain a daily diary between home and school. This way we could initiate discussions on what she had done at home or at school. As she was 'reticent to initiate discussion', this became an excellent way of overcoming her difficulty. When we have found people responsive to her needs and our suggestions, it has made life easier all round. If I remember correctly, the diary was our idea but the teacher was willing to give it a try.

Radhika's report, at the end of the first year in Bradbury Junior School commented on her adjusting well to a new school and new environment, progressing, if slowly, with her reading, and comprehension. Writing skills were improving in spite of a tendency to write quickly and therefore carelessly. Her number concepts were very basic and needed to be "related to her direct experience and frequently reinforced (bus fares, market prices etc)."

Since 'shopping' had been recommended by both the educational counsellor and her teacher, we introduced Radhika to our nearest supermarket — a ten-minute walk along the beach road. She accompanied me whenever possible and liked to push the trolley picking out items of her choice

as well as those I asked her for. She would stand with me at the cash register, fascinated by the machine but, with no idea of the money involved. Gradually she learnt to separate items and fill plastic bags in an organized way. Sometimes I would let her buy an ice-cream from the parlour — alongside, helping her to choose the right amount of coins from my wallet, encouraging her to ask and pay for it herself.

One evening she left the flat unnoticed and could not be found anywhere in the compound. We walked down towards the supermarket. In a few minutes she appeared round a bend sobbing her heart out. Apparently she had asked for her favourite vanilla ice-cream, been given it, but then having no money to pay for it she had had to hand it back. On this occasion she had shown both initiative and independence but had taken no money to pay for the purchase. My shopping lessons were obviously going too slowly for her. I began to let her carry some money in her own bag and pay independently for her purchases. In retrospect, I realize that she was not given enough opportunities, in Hong Kong or later in Sydney, to learn to shop on her own.

That year Radhika attended a Primary 6 class camp organized by the school. The children were to be away from Friday to Monday, and she was given a list of requirements, all of which had to fit into a rucksack she would carry on her back. It was good to see her excited and happy. She helped to read the list, collect the items and then pack them in. This was the first camp she had been to in her life. She was off with all the 'normal' children of her age, knowing them from shared activities in school and eager and happy to go. Without her, home was a little strange, but the rest of us enjoyed that weekend too. We missed her cheerful presence, wondered what she was doing during the day, but also felt relaxed.

She returned on Monday, brown as a berry, full of her camp and activities, saying she had had a 'wonderful time'

and hadn't missed us at all. It was an excellent experience in independence. Her teacher's report indicated what a success it had been, and how she was "very content at looking after herself and confident with the other children and adults."

Altogether she had had a very successful year in school, and was now being transferred to the secondary South Island School with four other children also eleven and ready to move up. Her teachers had "thoroughly enjoyed having her in the unit and would miss her very much." On the last day of school her teachers and friends wrote on her pink and white check uniform, wishing her well and saying goodbye. She came home that day elated and grinning from ear to ear.

Of the five children who were 'promoted', Annsen and Radhika had Down's, Bhaskar, Aungkhine and Laurie were possibly brain-damaged. It was school 'policy' not to discuss the medical history of one child with another child's parents; it was sufficient to know that each had some difficulty or other and all were together in a special class. Of this group, Annsen was Sino-American, Radhika and Bhaskar Indian, Aungkhine Burmese and Laurie British.

South Island School was a senior school in Hong Kong's English Schools' Foundation system. They had agreed, as a trial measure, to have these five children transferred from the junior school into a special class within their school. Seats in the junior school unit were required for new children and in any case it was considered advisable to move the eleven-year-olds with their normal peers into the senior school. It seemed reasonable, yet we were somewhat apprehensive; there would be a new teacher, a new and bigger school, and a new beginning for Radhika. We had to wait to find out that our fears, however natural, seemed always to underestimate her capacity to adjust and settle.

Chapter Eight

Once a year, during the long summer break, we would return to India and the family in Chandigarh. Radhika disliked air journeys and wanted to travel by train or car. We showed her the atlas, how there was an ocean of water to cross, how planes get you home faster and so on. She showed an interest in the map, but how much she understood, I'm not sure. She could read the names of familiar cities and even locate them, with help. The world weather report on TV had familiarized her with names of capital cities, temperatures and common words to describe the weather. Once learnt, she has often recalled information correctly and in the right context. Sometimes she will say things out of context, but mostly the information will be correct; it is important, therefore, to give information about and exposure to as many places, people and things as possible, since children with disabilities learn better and more easily from direct experience — which all goes to make them happier and better adjusted.

In Chandigarh there were two family homes — Nani and Nana's, and Dadiji and Auntie Cuckoo's. Nani had been a great friend and companion to each of her grandchildren, genuinely enjoying their company and doing things with them. Radhika was physically small for her age, and enjoyed simpler games and chats. Nani has a remarkable ability to come down to any level, and so there were squeals of laughter during their daily card games of 'donkey', 'gulam chor', patience or 'panj patti'. Nani would take her for walks to the

market, or to visit friends. Their chatter was easy and companionable. Sometimes Radhika would help her use the mixer for beating eggs, or shell peas, or some such small task in the kitchen. Radhika has always had a very soft spot for her Nani — not difficult to understand when Nani has done so much with her.

Nana had a different relationship altogether. Though she was no longer the little baby he had wished her to remain, he would tease her, just as he had teased the other children, ask her the same question over and over and get her worked up: like, "Dimpo, why do you like 'dahi' in the summer?" Her invariable reply would be an emphatic "I will." It made no sense, but each time it amused the family. He enjoyed her in his own fashion, enjoyed her strange, busy little ways and her funny answers, her scuttling off when he tried to pinch her little bottom. I think he found her as fascinating to observe as he did his other grandchildren, and as amusing.

As for Dadiji, she loved having her over, feeding her with her favourites, 'dal' and 'chawal' and 'paneer', even keeping eggs for her breakfast in an otherwise totally vegetarian household. Dadiji would rummage out old photographs of Ramesh as a child. Radhika enjoyed this and couldn't quite believe that her father had been a child once. 'Lealy' she would say. The 'r' sound was hard to make clearly, the tip of her tongue not quite able to reach her high palate. Cuckoo, full of energy as she has always been, invariably had dozens of things to get done, garlands to string for the *puja* room, flowers to gather, beads and baubles to make decorative things with, and the daily vegetables to wash and cut. Radhika was fairly bulldozed by Cuckoo's drive and pace but enjoyed all the activity.

After our first holiday in India, Sandhya left for Mount Holyoke College in the U.S. The family had been together for a year in Hong Kong after the five years Sandhya and Aarti

had spent in boarding school at Sanawar. We missed Sandhya sadly. In August 1984, Aarti too left us for the same college. Now our home was empty. Radhika still had a full school life, but at home she was alone with just her parents. This separation was bound to come, for us and for her. Both sisters had a good relationship with Radhika who enjoyed their company very much. Together they laughed, teased, bullied and chattered; there was no way I could replace their youthful excitement and joy of life for her. Inevitably, she was faced with adult responses, adult forms of entertainment and conversation. This had its good side, for she began to mature. But I know she longed for the holidays when Sandhya and Aarti would visit and cheer us all up.

Dina Guha had explained early on the importance of keeping Radhika slim and active. She had said Downs' children especially liked to eat too much, and because of slack muscles they usually preferred to be inactive, thus getting fat and flabby easily. If overweight, they became mentally as well as physically lethargic. Radhika's diet, therefore, had to be carefully supervised from the beginning, and as she approached her teens we had to be even more conscious of weight gain than we had been earlier. Radhika's sisters have been excellent role models in this respect. Both girls have encouraged Radhika to take pride in her appearance, to control her appetite, to take exercise and often to go on a diet when she has put on weight. She has only to be reminded of what Sandhya and Aarti will say about her 'fatness' to put herself immediately on a diet. Over the years we have noticed how much more active and alert she is when her weight is under control. Now, thanks to Sandhya's and Aarti's efforts she is herself a little more conscious of her looks.

In Hong Kong we had a constant stream of house guests, all of them close family and friends who knew Radhika well. Eating out was a special attraction and Radhika joined the

grown-ups on most occasions. On the other hand, she disliked shopping and preferred to stay home while we went on these expeditions. However, she enjoyed taking our visitors to the extensive Ocean Park Aquarium and the amusement park at Lai Chi Kok. Sometimes I would stay behind telling her to be in charge. She liked this as it gave her a feeling of independence. She began to enjoy the mainly adult company she had and learnt to accept the separation from her sisters.

One summer, only Radhika and I came home to Chandigarh. There she had a bicycle with support wheels, which she rode easily and well. Chandigarh was a good city for such activities. We, or was it I, decided that she must learn to balance without the support wheels, and bicycle like a 'big girl'. Well, the task was undertaken. Across the dusty but open maidan I would run behind the cycle, holding it, and stopping it, but telling her and showing her what she must do. This was a daily exercise. Gradually I would leave her on her own. She would manage to cycle a short distance, then topple, and immediately turn back to see where I was. Toppling over, I explained, was all part of learning; she must learn to fall as safely as possible, and so on.

Weeks later, she had got it! Her joy and excitement were unbounded; now we could cycle together. She kept her balance, watched out for traffic, managed the roundabouts, and could use her brakes — indeed an achievement. Every time there was a long break, she would lose her self-confidence and nerve. Then, after coaxing and a few practice runs, she would be game to go again.

Part of this reaction was natural, but she clearly lacked self-motivation and confidence. Her fears were more marked than a normal person's and, for her, the first reaction was to give up. She needed more encouragement than other children, and whatever she did learn, she learnt more slowly, more painstakingly. We had to be patient and encouraging all the time

if we wanted her to try again. This has been the case with so many activities, and however exhausting, the experience has been rewarding, both for her and us.

Chapter Nine

In Hong Kong, as elsewhere, we went to all the shows and concerts we possibly could, taking Radhika along whenever we felt she too would enjoy the performance. Her invariable response would be negative. Once, we had tickets for the famed *American Holiday On Ice* show and were excitedly looking forward to it. It was to be held in the largest indoor stadium which accommodated thousands of people. The usual explanations were given to Radhika and we tried enthrusing her but with little success. On the day of the show we arrived at the stadium and were at once in a sea of people, faced with stands rising high on all sides of the central performing area. Our seats were halfway up, but Radhika stood transfixed and would not move. No amount of prodding helped. She now wanted to visit the toilet. I was irritated and impatient and waited while Ramesh took her off. Eventually, holding my hand and his, she made her way up slowly and at last we were seated. She looked very unhappy. I gently asked her what had upset her. "It's the spaces between the stands that make my head go round," she replied. Spatial disorientation, I remembered Dina calling it, and explaining how necessary it is to overcome it by making her aware of her body in space and showing her how she could cope confidently and safely in various spatial situations.

Unfortunately, we do not always understand her hesitations and often she is unable to identify her fears, so that a real difficulty is quite often seen as an intransigence. After

the usual fear and hesitation on every single day of the show we took her to, we found she really enjoyed each programme, whether music, dance, mime, ballet or film. She needed to visit the toilet at least once before the performance and we had to leave enough time for this to take place leisurely.

As she grew older, she wanted to know what the show was going to be about, had she been to that theatre before, and required plenty of time to get used to the idea. Later still, she wanted to be given a choice, and we sounded like we were doing just that, while in fact we were persuading her, ever so carefully, to choose to come along because she would enjoy doing so. We could no longer take her acquiescence for granted.

Radhika has tested my patience on many occasions, often making me feel guilty for my responses. Each time I have had to work through my 'guilt', accepting my own frailty or tiredness as a contributing factor, forgiving myself, accepting that I, too, make mistakes in handling her, and am not, and indeed do not have to be some sort of 'superwoman' or 'super mother'.

In 1984, for instance, when her *nana* and *nani* were visiting us in Hong Kong there was a real drama. We were having tea in the sitting room when Radhika walked up, stopped near the front door, picked up something from the tray nearby and walked out. She could use the lift on her own so I did not envisage any trouble. Fifteen minutes later however, I heard a big thud from down below and checked the tray to see what she might have taken — the car keys were missing. With my heart pounding, I went down the lift. The thirteen floors took interminably long, but imagine my horror when I saw that the car was out of the garage, had crossed the drive-in and had hit the wall on the other side.

There was a small crowd around the car and a surprised and frightened Radhika at the wheel. I lost my head in rage

and fear and shouted at her. She shouted back at me, got out, slammed the door shut and, still shouting, marched off the scene, into the lift and up to the safety of her room. She was frightened by the big bang against the wall. Her pride was hurt by my shouting at her in front of everyone, and she in turn lost her head and shouted back at me.

When we had both calmed down, I asked her to tell me what exactly she had done. It emerged that having noticed how the car engine was switched on, she had proceeded to imitate an adult driver without knowing what she was doing or how dangerous the consequences could be. It seemed she had switched the engine on, put the gear into reverse and then not known how to stop the car. Mercifully the wall had stopped it, and no child playing had been knocked down; Radhika was safe though terrified and the only damage was to the car, the wall, a flower pot in the way and our nerves.

She was given a long, serious talking to, and we still remind her of the dangers of attempting to drive when she doesn't know how. I have read of young men and women with Down's Syndrome learning to drive and turning out to be cautious, reliable drivers. Unfortunately, in India where drivers do not follow the rules of the road and the unexpected happens all the time, it is not safe for Radhika to drive. I do believe she could be taught, and could learn to be a safe driver, but in a saner city than Delhi.

In July 1983 schools reopened in Hong Kong for the new academic year. Radhika's new uniforms were the same as those worn by the children in the normal sections of the Senior school. I took her in on the first day. We met her teacher, this time a Scotsman called Doherty, trained in special education but new to the South Island School. He was warm and friendly. The classroom was larger and arranged in different sections — one for painting, one for cooking, one for written work and one for reading and playing board games.

The 'special' children were nervous, but Mr Doherty put them at their ease, explaining all the activities they would be involved in. He reassured the parents too. Our children would join their normal peers for assembly, music, cooking and hobbies at first on a trial basis, then as a routine if successful. At breaktime a few youngsters from the normal classes would drop by to visit and 'make friends'. Thereafter everywhere we went in Hong Kong we found Radhika being recognized and greeted by this friendliness. Although, of course, it was only superficial, it meant a lot to her. It doesn't require too much to make these children happy.

The term 'special' has been used to describe children with a disability having 'special' needs which require 'special' attention and 'special' facilities. Terms have changed over the years, becoming less odious and more humane and natural. Children with a physical or mental disability are children first, and this is important to remember.

When little was understood about mental disability, children with retardation were equated with the mentally ill. As more knowledge has been gained, so more has been achieved and attitudes have changed, however slowly, as has the nomenclature, from retarded handicapped to learning disabled and now to 'mentally challenged'. There is a growing recognition that environment and society create further 'handicaps' for the disabled by not providing adequate facilities.

Today, some young people have learnt to acknowledge their disability, and have acquired enough confidence in themselves and their achievements to say, as Radhika once did, "I have Down's Syndrome and that's why my feet are bad." She has Down's, I have high blood pressure, and each of us gets on with living the rest of our lives as normally as possible.

Soon after Dina Guha had started her programme with Radhika, she took us to a meeting of the Bombay chapter of

the National Federation for the Welfare of the Mentally Handicapped. Several eminent people and a few parents attended. Discussion became heated, as I recall, when Dina objected very strongly to the name of the organization. Her contention was that 'People with Mental Handicap' was more appropriate, as they were 'people' first and handicapped afterwards. At that time I remember thinking that this was just hairsplitting. The wisdom of her words dawned only after Radhika started asserting herself as a person and I accepted her as such.

Once the children had settled in and Mr Doherty had got to know them, he started weekly outings with them. They were taken to several Chinese markets and shown their special features — the fruits, vegetables, fish, poultry and meats and how they were arranged and sold. Often the children would buy some small item, thus being exposed to money and purchasing. They took the ferries, the car ferry being a particular treat which none of them had experienced before. Mr Doherty also organized weekly riding lessons at the Jockey Club and sometimes, very special times they were too, he would end an outing by inviting them to his home for pancakes. Radhika grew very fond of him. She would often come home with a pen she'd stolen from him. When, slightly embarrassed, I mentioned this to him, he said, "Think nothing of it — this is a game between us."

One outing Mr Doherty was able to arrange was a visit to the liner, Queen Elizabeth II, popularly known as the QE-II while she was berthed in Hong Kong harbour. The children were terribly excited. The visit to the luxury liner was an eye opener. They had no idea that they would see swimming pools, tennis courts and ballrooms on board. They were shown around the engine rooms and the cabins and then visited the Captain for a drink and a chat. Radhika returned that afternoon full of everything she had seen and talked of

it for days afterwards. It was through such experiences that Mr Doherty introduced new words and new concepts.

We had welcomed our children's friends to our home whether in Bombay, Delhi, Calcutta, or now in Hong Kong. I took the initiative to invite Mr Doherty and his students to lunch one afternoon. He thought it was a good idea and a day was fixed. He must have discussed with them how they should behave. Quiet, and somewhat ill at ease the first time, when they came again, six to eight weeks later, they chatted, laughed, and enjoyed the food and music more naturally. Radhika was in her element and the one most at ease. Indeed, she had always enjoyed playing hostess, and been very clear about what she wanted to do. It was interesting to watch her goad the others into eating and dancing and, as is normal in any group, one or two always resisted quite firmly. Her bossiness had to give way, and this was good, for in trying to compensate her I am sure we have let her have her own way too often.

The lunch visit became a regular feature. Group dynamics in school are of one kind, out of school they are different again. Radhika felt important but had to learn to give importance to her guests and their wishes. It gave the children an outing to look forward to, to discuss in school the next day, and talk about in their own homes.

It took nearly two years of this routine to elicit a similar lunch from Annsion's or Aung Khine's mothers. I was the only parent to be invited. The children saw two other homes, behaved well at table, and got Chinese and Burmese food instead of only Indian. Used to being an only child at home and generally getting her own way, in the homes of her friends she had to fall in with their ways and wishes. Doherty had remarked on her ability to lead others in the classroom, but her bossiness needed tempering and this was an important lesson for her.

Towards the end of the second academic year, Mr Doherty was advised that he would have to move the unit across the harbour to Kowloon to a special centre built to house only the special education unit. It was found that teachers in the normal school could not cope with the additional burden of five slow learners. Also, parents were objecting to the large amount of money spent on specialized equipment and the school board was unable to justify this extra cost for just five children.

It was going to be another move we could not avoid, and we had mixed feelings about it. The large normal school offered a 'normal' atmosphere. Our children were not segregated; integration with their normal peers was excellent for them. I feel sure their presence was beneficial to the whole school community. We felt let down. However Mr Doherty explained that he would have more funds and support from the Department of Special Education when he was on his own. There would be no school Board of Governors questioning expenses, and he could gear their programme solely for the 'special' children. We knew he was disappointed too, but we had to make the best of it. I recall that the parents wrote a joint letter explaining why we would prefer to have our children integrated in the South Island School community and requesting that they be allowed to continue as before. Back came a reply virtually telling us that we would have to accept this move or withdraw our children altogether.

It has been very hard for me to accept that Radhika is subnormal; that children her age, with normal intelligence, don't have much time for her; that she cannot participate in their conversations at their level. This is part of the pain these children give, and what we must learn to accept and overlook. For if we don't, and overprotect them, we make them and ourselves more vulnerable, and then we are all the losers.

The South Island School experiment in integration had not

succeeded, partly because the costs were heavy and partly because attitudes were too rigid. Yet families with a mentally challenged child or adult have to change their attitudes, and learn to accept and accommodate him or her within the family. If society would also accept and made the necessary allowances, it would make bringing up such a child less difficult. The mentally challenged are not mentally ill. Reared with love, most people with a mental disability, especially Down's Syndrome, are not violent or abusive. In fact they are loving, gentle, generally reliable and quite predictable.

Radhika's almost two years in the 'special' class of the South Island School saw her make good progress on all fronts. Mr Doherty's report remarked that she was aware of "the behaviour expected of her, her interaction with other members of her group was good and that she enjoyed leading the others in a wide variety of activities." Her reading ability, handwriting, word skills had made 'considerable progress', and in maths lessons she made a 'big effort to keep up with her assignments.' Cooking and metalwork taken by teachers in the normal section were found to be enjoyable, and she achieved 'a good deal of success.' Swimming lessons were proving more pleasurable as she overcame her fear of water. We thought this was a good report and were pleased and proud of her.

Her educational skills continued to improve though 'painstakingly.' Her reading scheme (Ginn 360) was up to Level 6, but at times she would, given the choice, choose much simpler books to read. She had made a 'concerted effort' to learn the days of the week and was now able to recognise them but not to sequence them as yet. Despite efforts made at home and in school, her concept of time was not well developed. She enjoyed cooking best among her special subjects and 'is aware of the dangers in the kitchen, and is competent in most aspects provided there is supervision.'

To quote more fully from the same report, under general comments, "Radhika has grown up quite noticeably this year. She can be very obstinate from time to time and when confronted will entrench herself. This is particularly noticeable when her routines are disrupted. Usually, however, she is a very happy and helpful pupil. Many comments have been made by teachers in the school who have observed her concern for other students in the Unit. She will readily take students for walks around the school. She is reliable in school and willing to help with tidying up and putting things away in their correct place. Frequently she will volunteer to do chores which the other students are happy to avoid eg. washing and drying dishes."

It is apparent from this report that while Radhika did show stubbornness in school, her 'tantrums' were reserved for home. She knew that her shouting and banging of doors would not be tolerated at school, and would in fact 'let her down' in front of her teacher and her classmates. Mr Doherty never tired of telling me how he had an easier time with her because of the presence of her friends and because he had them to compare her with. She was giving us a hard time at home and rather like the little girl with the curl in the middle of her forehead — when she was good, she was very very good, but when she was bad, she was horrid. I used to repeat this little rhyme often, she would giggle and refuse to believe she could be like that. But more of this later.

In May 1985, Mr Doherty referred Radhika for a review of her learning ability to an Educational psychologist of the Special Educational Section of the Hong Kong Department of Education. Ms Hui had two interviews with Radhika, who impressed her as a 'friendly and sociable girl who related to me readily.' However, Radhika, true to form, was not very motivated or interested in doing the academic tasks and tended to give up when the items were difficult for her.

Intelligence testing, using the Wechsler Intelligence Scale for Children (Revised) suggested "that she was considerably behind a child of her age in both verbal and non-verbal reasoning abilities. Present findings generally consistent with the previous assessment suggest that she is performing at a concrete level. This is quite typical of Down's Syndrome children who find abstract thinking a problem."

The advice given was basically the same as when we started with Dina — that is, help her to be independent. Radhika had learnt early self-care skills — under Dina's guidance; now in her teens, these had to be extended to include social skills. For example, taking a bus to school, going to a post office to buy stamps or post a letter, going to a bank to deposit or draw money and going to a restaurant, ordering and paying for a meal. These skills would be useful towards leading an independent life in the future. Physical exercise like swimming, cycling and ball games was recommended as before and for the same reasons: to increase and improve eye-hand coordination, balance and posture, and provide suitable leisure activities.

We seemed to quite easily slip into expecting from Radhika the normal 3R skills for their own sakes. These regular assessments, far from being repetitive and tedious, corrected our direction and suggested that Radhika was ready to learn more advanced activities. We were unable to do all that was advised, but we did introduce her to the post office, and to ordering a dish if not the whole meal at restaurants.

In the new academic year beginning August 1985, the Special Education Unit was moved from the mainstream South Island School into a new and independent building in Kowloon, called the Sarah Roe Centre for Special Education. A special bus picked them up from their homes and returned them after school. It was a longer day, but the children took it in their stride. Although cut off from the mainstream

students, Mr Doherty filled their hours with activity. The Centre had space for the old equipment and several additions. The garden was used for planting seeds and the children learnt something about gardening. There was great excitement when they put together a chicken coop and bought hens and feed. Looking after and cleaning the coop became a part of their routine.

Shopping and cooking continued as before. A couple of computers were provided, and the children were taught two-finger typing. Swimming, horse riding, trips on public transport, picnics and outings were all part of the Centre's weekly programme. One day Mr Doherty arranged for the children to spend a night at the Centre after school. They took a change of clothes and a sleeping bag each, and shopped for their tea and dinner at the local supermarket. That evening they stayed up late, enjoying their night out and indulging in a midnight feast. It was a great success and was repeated once more as a special treat. The advantage now was that Doherty could plan the programme solely for the benefit of his five or six children, at their pace and without disturbing the routine or making financial demands on the main school. However, we paid the same school fees as in the normal British schools, which though not as high as the American school, were much higher than any we had paid in India.

Radhika had been in three special education units in Hong Kong alone, each with a good programme and skilled staff. So far she had been extremely fortunate in all her moves, both within India and in Hong Kong, each time moving to better facilities and making further progress.

Chapter Ten

No longer a little girl, Radhika had shown signs of puberty at eleven or so; a slight swelling of the breasts followed a soft down under her arms and in the pubic region. I now had to prepare myself to introduce her to menstruation and the physical changes taking place in her. It was comparatively simple to show her my own body and point out her developing breasts and hair. It was more difficult to work out how best to explain the monthly period, how to use sanitary napkins, dispose of them correctly, to keep this an area of privacy, neither to talk about it in company nor to leave soiled napkins or panties for others to see, clean or dispose.

The fact that she could become pregnant once her periods started was the most formidable task to explain, and to satisfy myself as well that she had understood. After very careful thought and recalling Dina's advice to go 'step by step', I decided to tackle first what was going to happen first. So that she could understand, I first showed her my own body and referred to her older sisters, now eighteen and twenty. She would develop like them, slowly but surely. "See how they look, how they shut the door when they bathe and dress. They don't appear half-dressed; grown-ups behave modestly. She was now 'growing up' and she, too, would have to be discreet and guard her privacy" — these explanations were made repeatedly. Sandhya and Aarti too would help to reiterate the same points again and again.

The next step was to tell her about menstruation. "Big girls

of your age all start their periods", I explained. "It is a flow of blood (but not from any kind of hurt or injury) which comes every month, for four or five days. Your sisters have theirs, I have mine. This is natural and normal for all girls. You are becoming a big girl now, growing up, becoming a young woman like your sisters," (how much easier to have them to refer to). I had a picture book to help us, but she related better to her sisters. Then I waited for my next period, showed her the blood on the panty, how I cleaned and dried myself and put on a sanitary pad. I washed out my soiled underwear until it was clean, and then I went about my normal work and life. Also, I had to show her when and how to change, how to wrap up the soiled pad carefully and put it in the bin in the bathroom so no one else saw it — just as every girl else did.

Over the years, I had often wondered how she would manage the whole business when she came to this stage in her life, and also whether she would be able to do so independently. Now she was nearly there, and I was struggling to explain, demonstrate, repeat over again, in good time, so that she wouldn't be shocked or frightened, and hopefully would learn to cope.

I had thought that menstruation would be an insurmountable hurdle for Radhika. When it happened, I wasn't even with her. I had taken off for a week to visit Bombay. Ramesh, my parents on visit and Celina, our domestic help were there in Hong Kong.

Ramesh got a call from Mr Doherty in school telling him that Radhika's period had just started, and asking him to please take her home. When she got home, her *nani* and Celina got her organized. She showed no shock, no surprise and was quite excited at being a 'woman' now. She knew she must be private, and handled herself with aplomb.

The day I returned, she came home from school, saying

"Guess what? I started my period. Now I'm grown up." I was amazed how easily it had all happened. "It's very private, I don't talk about it to anyone," she added. My heart rejoiced as I hugged and congratulated her.

It was Mr Doherty, teacher of three pre-teen girls ready to start menstruation, who became beetroot red with embarrassment when it happened, suggesting that we should keep our daughters at home during their periods. I remember laughing and telling him that this was neither desirable nor necessary. And it wasn't. We kept a record of the dates and, of course, Radhika was reminded to organize herself in time. She continued to do all the normal things, and never let herself down by word or deed.

Mr Doherty reported in June 1984 that "the arrival of her menstrual period is a very big step in her physical development. She has overcome any traumas attached to this and is very matter-of-fact about it when we discuss it with the others." She had also coped "quite well with the normally difficult transition from primary to secondary school."

Within a few months she became quite proficient in caring for herself during 'those' days. The initial excitement wore off, and she began to say how she wished it would go away and how much she hated it — all natural reactions. Now that she could become pregnant, however, we had to consider how best to explain the need to safeguard her from this fresh danger.

I belonged to a culture and an age in which sex and sexuality were not discussed at all, let alone with youngsters. When Sandhya and Aarti were teenagers, I was able to overcome some of my inhibitions so as to prepare them for their first menstrual period. Five of their important growing years were spent in a boarding school. Although it was a co-educational school, the children were kept carefully apart. Besides, until they were fifteen or sixteen, they seemed to be

more interested in games and sports than their male peers. And by then, I had hoped they would have studied biology and understood how pregnancy occurs. In any case, within our family, as in the Indian context of the time, it was understood that sex came only after marriage.

In Radhika's case, we knew that she could easily be taken unfair advantage of by unscrupulous men. She was innocent and trusting — a fatal combination. I knew of such cases personally, and was quite petrified of the possibility. It was not only sexual assault that frightened me; now that her periods had started the possibility of a pregnancy loomed like a nightmare.

Radhika's sexuality was developing at the same time as a tentative interest in boys. Like others with her disability, she was lacking in inhibition as well as discrimination. Explicit TV programmes and the fairly free behaviour of young people on the streets and beaches of Hong Kong, acted as an example and an impetus. We had to contend with all these factors and find a way of making her aware of the dangers. Moreover, the chances of her producing a baby with Down's Syndrome were high — fifty per cent we had been told — nor would she be able to take full responsibility for a child, even if she could go through with delivering one.

We sent for the relevant books from England, case studies and literature on sex education, marriage, etc. for the mentally challenged. We read everything we could. We wished she could marry when she was older, but we never wavered in our conviction that she must not in any circumstances become pregnant.

Complicated issues are difficult for Radhika to appreciate or understand; she cannot easily discriminate between differing circumstances or situations. It is easier to explain to her, and easier for her to understand, a straightforward issue which is clearly right, or clearly wrong. But life is not so

straightforward; we had made a deliberate choice to make hers as full as possible, so now our task was more difficult and complex and there were already some worrying indications.

Radhika's sexual stirrings had first been satisfied by her doll Blake. Now, for example, we sometimes found her kissing or hugging a friend she had asked over to the house — boy or girl made no difference. There were a few embarrassing instances so we had to keep a watchful eye on her, especially as we did not want her to be isolated from her friends. We just had to take it day by day, step by step, talking it over with her, explaining what was unacceptable and encouraging acceptable behaviour.

Having reached puberty, there were bound to be tantrums, outbursts of anger and bouts of obstinacy and sulking. This I was expecting; we had lived through both Sandhya's and Aarti's teens. But what we weren't expecting were her uncontrollable rages when she would scream, shout and bang doors. She was now bigger in size too. I was baffled and stunned by her rages. Their intensity seemed to threaten both me and my authority. If I expressed displeasure, she would get further incensed. Her reaction would make me tremble with anger and frustration. It took many such outbursts for me to realize I must not try to reason with her when one was building up. Instead, I must remain calm myself and ignore her as suggested by Mr Doherty, never letting her know that she was in fact unnerving me. It wasn't always possible to manage. I kept in close contact with her teacher so that he could talk about this more impersonally in class and also advise me from time to time.

When the rage had passed she would look contrite, but never could she say she was sorry. She had her pride. She would stand in her door and look forlornly at me until I went to her. Then there would be a period of good behaviour

followed by another sudden outburst as if she was possessed. Growing up was not easy. Many years ago, Dina had told us about 'phases in development', how a period of physical growth was accompanied by stress and storms on the emotional front, and how this was followed by a period of relative calm, when it would seem physical growth was slower and more in tune with emotional development. This had made great sense in understanding our older girls. Now it was true of Radhika also, except for one difference — that Radhika did not know how or when to control herself. She was less able to understand, nor could we be sure how much she had understood. She did know that we were upset, and this she didn't like at all. She needed acceptance despite her bad behaviour and as a result her remorse was always genuine.

There were many times when I felt I could no longer cope. I would become physically exhausted and emotionally drained. From the period 1983-84 onwards Sandhya and Aarti were not there for her or to help me, and Ramesh was frequently out of town. I reread Dina's notes, read books on teenagers and wrote copious letters to my mother. Sharing my difficulties with Radhika's teacher also helped.

At fourteen years, she had not outgrown her tantrums though their frequency had decreased. 'Confronting' her still threw her into an uncontrollable rage, but I was better at turning my back in good time and ignoring her. When I too lost my temper and patience, we would be facing each other, shouting and threatening, having reached a complete impasse. It was a relief to remember, however, that she would eventually grow out of this stormy developmental phase, like her sisters had done earlier.

When she wasn't raging we shared happier activities like cycling, for instance. On the small island of Hong Kong there were only a few good paths for walking. One of these paved paths went along the seafront from Repulse Bay, not far from

our apartment, to Shousan Hill a mile or so away. Often Ramesh would take Radhika down to it with her bike. It was not level all the way, so cautiously Radhika would get off and walk the bike down each slope. Gradually, Ramesh taught her how to use her brakes gently enough to keep the bike going, but not too fast.

One day, when he thought she was fairly confident, I was asked to go along to see how well she managed. She was eager to show off her newly acquired skill. She cycled ahead while we walked some distance behind. She did not realize however that she was gaining speed as she went downhill, nor did she use her brakes. There was nothing we could do but watch and hope that when she fell it would not be near the sea edge of the road. She duly fell off. We rushed up — she was bruised and terribly frightened. That little puff of confidence had vanished. Ramesh had to work doubly hard to restore her faith, but she didn't forget that fall for months.

Such setbacks in self-confidence are extremely difficult to overcome. Perhaps this is why we have tried to make sure she doesn't have them too often. We have had to teach her step by step, then let her go at her own slow pace till her assurance is firmly established. We have had to remind ourselves not to push her faster or beyond her natural inclination. Yet, lazy and negative as she tends to be, she wouldn't have learnt a thing had she not been pushed, slowly and firmly but pushed nonetheless.

Along this same path, on Sundays there would be several Chinese fishing and catching crabs. Celina loved fish and decided to take Aarti and Radhika down to the rocks for a spell of catching crabs. Arming themselves with small nets, thick towels and buckets, they walked off one Sunday afternoon to see what they could catch. It was an activity they enjoyed and in time became quite good at. We had crab curries and fried fish several times. Radhika tried her hand

at it as well. Her nervousness gave way to great excitement when she managed to catch her first crab — it was the largest one so far. As the interests of the sisters differed more now than in earlier years, I was grateful when some activity such as this was shared and found pleasurable by all of them.

At this stage Radhika began to express a natural curiosity about death, and what happens to the body after death. She was only a year old when Ramesh's sister died in 1973 and therefore not aware of the death, or the sorrow it entailed. The first death she was old enough to worry about was the death, in a road accident, of her pup in 1978. In 1984 when her pet hamster died in Hong Kong, she not only saw his lifeless body in the cage, but she and Celina actually buried it on the hillside nearby. We used this concrete experience to explain life and death, the different ways dead bodies can be disposed, some of the more frequent ways death is occasioned and that while it is sad to lose a loved one, sometimes death can be a release from pain, serious illness or just old age. In any case it should not be feared; no, we could never see the dead person again, but, yes, we would miss and remember them.

Of the three grandparents alive, it was her *nana* who passed away first. It was just as well we had taken the trouble to answer her questions about death seriously, for though she now felt bereaved, she did understand better what it meant. When Ramesh and I got back from Chandigarh after his death, she wanted to know everything and we were able to tell her that his body had been cremated, and how we had driven to a lovely canal to set his ashes free in the gently flowing river. She showed great interest and wanted details repeated and explanations given, which we did.

She had loved her *nana* and enjoyed a special relationship with him, so that it was quite natural for her to remember him. Sometimes we would catch her, sitting alone and crying

quietly. "I'm missing *nana*" she would say. A loving cuddle and a few soothing words would help her recover. On the following visit to Chandigarh, she knew she wouldn't find him there with her *nani*.

About then, we noticed Radhika was beginning to develop a fascination for the macabre. She was eager to hear from us about accidents and murders reported in the press or on TV, and her fascination persists to this day. She may not be able to distinguish a serious road accident from a minor one, but she comes home and tells us about it, embroidering the gory details animatedly.

There is a genuine concern too, for she does notice whether others have helped the injured and if not, she wants to call the police herself. I wonder if perhaps she wants to involve herself thus from a desire to be helpful and therefore more useful and needed.

Anson Chou was Radhika's very special friend from school, and had a sister in Aarti's school. I had met Mrs. Chou several times at both schools and now decided to ask Anson over for a weekend. We weren't sure how it would go, but Radhika was excited at the prospect. Mrs. Chou warned me how Anson was very nervous at night and went to sleep with some difficulty. All the same we decided to give it a try.

Anson came in the late morning. She was bigger than Radhika and her speech was not as clear. The two girls enjoyed being together. That evening we had been invited out to dinner. My parents were visiting and Aarti was home so we felt it would be alright, and left our phone number with them. At nearly 11 pm we received a distress call from Aarti; Anson would not go to sleep. She had been muttering and groaning and nothing anyone said or did could calm her down. We left at once and came home to find Radhika very tired and fed up, Anson sure there were 'monsters', and Aarti and Mother quite defeated. I told her very firmly to keep

quiet and go to sleep as there were 'no monsters in our house.' I had to repeat it twice and then she was asleep!

Mrs Chou had asked me to let her know whether Annsen had behaved acceptably and if there had been any problem. This feedback was important, we both knew. While I did not make too much of it, I did tell Mrs Chou how Annsen had not been able to fall asleep herself, nor had she been quietened till eleven pm when I returned. Mrs Chou was grateful to have been told.

The next overnight stay was easier for both of us. The Chous had Radhika stay with them a couple of times and found her no trouble at all. Radhika had stayed over many times with different people from an early age and did not feel anxious in other, familiar homes; in fact she always enjoyed these outings.

During our four years in Hong Kong, we travelled with Ramesh once each to the Philippines, Bangladesh and Thailand. Radhika and I both dislike flying, but her experience and vocabulary increased tremendously with the formalities of security check, passport control, immigration, baggage clearance and custom, and all the words associated with planes and flying.

We also did a lot of sightseeing; in Bangkok, where Radhika and I went about on our own, she saw 'Buddas and more Buddas' until she'd had her fill and never wanted to see another. On the whole she made an excellent tourist, didn't fuss about the endless walking and sightseeing, and was good fun to be with. It is amazing, too, what a good memory she has for events and places and people.

While in Hong Kong, Radhika was gradually introduced to cooking. She loves food, so this was and always has been a pleasurable activity. She learnt to light the stove and fry herself an egg. When she could turn it over without breaking the yolk she was thrilled. If sometimes she broke the yolk,

she would generously give it to her Dad or me, saying that she had cooked it for us. Then she would make another one, more carefully, for herself. She also learnt to scramble eggs and make an omelette. But most importantly she used the stove safely. Thanks to Dina's early training, she could also pour and fill glasses and jugs and carry plates or water jugs. She has always been very careful, and I can't remember any occasion when she broke something from careless handling.

Hong Kong was great for teaching us the value of doing things for ourselves. We made our own beds, laid the table for meals, helped clear and wash up. We did the laundry ourselves and Radhika helped to hang up the washing. We did our own marketing and Radhika helped here as well. Although we had domestic help, we put our hands to everything and learnt the dignity of labour, while sharing household chores.

Chapter Eleven

During our stay in Hong Kong the only medical problem we faced on account of Radhika was to do with her teeth. Fortunately, our dentist in Calcutta had given us an introduction to Hong Kong's Prince Philip Dental Hospital. Radhika was called for her first checkup in October 1982 and thereafter for a monthly check and lesson in oral hygiene. David Kwong, the hygienist, taught her the best way to brush her teeth. He was a kind young man but he could not understand her extraordinary fear. She was afraid to sit in the chair, afraid when it was raised, afraid to open her mouth, afraid of all the instruments — of being hurt or forced. Four to five months went by in merely getting her to sit in the chair and open her mouth. However, when she finally learnt to trust David, she let him check and show her how to brush her teeth.

Meanwhile Radhika's permanent eyeteeth came out while the baby teeth were still there. The very first time I noticed this I got a real shock — it seemed as if they were growing backwards, into her mouth. I could hardly believe they were teeth at all. After examining them the dentist confirmed that they were permanent teeth. The baby teeth should be falling out, or if not, they could simply be removed. Terrified of doctors and hospitals after that earlier experience in Bombay, Radhika would not agree. We tried for months to convince her, but to no avail. Finally in 1983 it was decided to do the job under general anaesthesia in the children's hospital attached to the Dental Hospital.

We warned the dental surgeon that the only time she had had anaesthesia, for a tonsillectomy, she had nearly died. We produced Dr Dadina's written advice for the surgeon to see. He assured us that the anaesthetic used in Calcutta was very old-fashioned and that they had modern and better ones in Hong Kong now. Besides, he said, they had a lot of experience with such children. Nevertheless we were only half convinced and definitely got the feeling that although the doctors were confident they were not heeding our previous experience and present fears.

The date was fixed, the room booked. Radhika was wheeled in and the surgeon told us it would take under ten minutes; only a whiff of general anaesthetic would be required. She was wheeled out soon after. The surgeon said it had gone well, she should be awake in an hour and we could take her home by twelve noon. Ramesh went off to work, while I sat beside her and watched the minutes tick by into hours.

Radhika had neither stirred, nor opened her eyes. At one pm Ramesh came to take us home — but the nurse said, not yet. She hadn't come round at all and the surgeon could not be contacted. Fear rose in our hearts. She still hadn't stirred at six pm, when Ramesh returned again. He was angry and demanded the surgeon be sent for or at least contacted on the phone. He finally arrived at eight thirty — gave her a gentle slap or two, splashed cold water on her face, shook her up and then at last she stirred and opened her eyes briefly before relapsing into a drugged sleep. We could now take her home at nine — nine hours or more later than expected. She slept through the half hour in the car, all that night, all the second day and night, and finally got over the effects of the anaesthetic on the third day.

The surgeon requested certain investigations — he must have been taken aback, although we never had any explana-

tion from him. The head of children's dentistry at the Prince Philip Hospital said we should have a blood chromosomal study done, perhaps she had some other problem as well. Hadn't we done this already? Yes, of course we had, in Bombay, but to no avail as the blood was drawn from the wrong place and could not therefore be tested. Now it had to be done at the Genetic Institute. This was going to be difficult.

Not unexpectedly, Radhika was not uncooperative. We had to be ever so gentle, patient, understanding, and yet firm. Aarti was roped in as moral support for Radhika and me. She was also a little knowledgeable through her study of biology and genetics. We had to warn the nurses and technicians, explain the reason for her extreme fear and request them to take special care to reassure her. Thank goodness they did. Radhika put out her hand and the job was finally done. Some weeks later the chromosome study was ready — it was a case of Trisomy 21 and nothing else was found to explain her reaction to anaesthetic. It would appear that patients are individuals and simply don't fit into neat little boxes, invariably responding as expected.

We knew that Down's Syndrome was caused by a chromosomal error at the time of conception. Now to our great relief, we were told that Radhika's Trisomy 21 was due to nondisjunction, which meant that there were no hereditary factors that could increase Sandhya and Aarti's chances of having a baby with Down's. In other words, their chances were no greater than anyone else's. However Radhika's chances of producing a Down's child were as high as fifty percent.

The chromosomal basis of the Syndrome was identified in 1959. Research has been ongoing since then and today there is more information than when Radhika was born. In fact, even the dictionary definition of Down's has changed from

'idiot' to 'congenital disorder due to a chromosomal defect in which a person has a broad flattened skull, slanting eyes and mental deficiency (also called mongolism from some physical resemblance to mongoloid peoples)' — Oxford Encyclopaedic English Dictionary 1991.

Radhika had begun to show a more definite interest in boys in her thirteenth year. In her annual report that year, Mr Doherty mentioned her growing consciousness of the changes in her physical appearance, and the occasional accidental exposure of her bosom while in the pool. I remember feeling it was going to be harder now than when she was younger. She was also masturbating more. A beginning would have to be made in sex education. I sought out a counsellor. She told me in erudite and technical language what I already knew — that preparation in concrete terms must be undertaken at once. However, she emphasized that at this stage Radhika needed physical exercise more than ever to take care of the extra energy. So she started squash and group swimming lessons. Ramesh was a keen squash player and played at least twice a week while he was in Hong Kong. He began taking her to the Aberdeen Marina Club twice or thrice a week and was extremely good and patient with her on the squash court. At first she could hardly connect with the racket, but gradually improved. She had, thanks to Dina's early insistence, fairly good eye-hand coordination through various ball games and had even played a little badminton. This helped to improve her squash and she enjoyed herself tremendously. Ramesh would bribe her with the promise of a coke after the game — they would usually manage to play a complete forty-five minute session, and her stamina built up gradually. Soon Ramesh introduced her to serving and scoring, and they played regular games. She had to work hard at it, and each time 'won' a game or two off him. On their way out of the Club they would stop at a supermarket.

Radhika would select the right coins, go in and buy herself a cold drink.

I would sometimes go along to watch her — she has always needed my encouragement and approval to spur her on. Often this need of hers has irritated me. It has meant she is seldom able to do anything on her own, for her own enjoyment, her own satisfaction. And yet this isn't entirely true. She has been content to do various repetitive things without our approval or praise.

Aarti's Hong Kong International School ran a variety of two-week summer holiday courses. That year we registered Radhika for beginner's swimming with the 'normal' group at the International School. Radhika was afraid to enter the pool, and when at last persuaded she clung to the teacher's neck. After two weeks of group lessons, we realized she needed individual coaching if she was to learn to swim properly. Several enquiries yielded a Mr Wright, whom she called Mr R, and he soon understood her and got her going. He was an excellent swimming coach, and at a price gave her a thirty-five minute lesson five days a week for several months. I would take her and watch her at work. She began to make progress, managing without armbands, staying afloat, putting her head into and out of the water, breathing properly, swimming over-arm style, and on her back. Often she was lazy and didn't want to make the effort, but the promise of a coke after the lesson and further encouragement and coaxing would get her going.

As much as we had tried to hide our disappointment and impatience, I am sure she had sensed it all along. This was at least partly responsible for her unwillingness to try new activities, lest by failing she disappointed us further. Equally, her successes had been due as much to her own determination as to our goading her.

It is such a struggle with oneself, with one's ego, this

'accepting' of a sub-intelligent child. We have first to accept our own hurt, then work with the child to attain basic competence, nurturing and encouraging special areas of satisfaction and achievement, and ourselves learning to accept the child for what she is — not harping on about what she isn't, can't be, can't have or cannot achieve. Parents, too, need to be assured that they 'can do', and we have found, fortuitously I admit, that we too 'can do' a lot of things we thought we couldn't. The biggest compensation has been the love she has given — unquestioning love, 'like a puppy's' Dina had said — and with love everything becomes possible and worthwhile.

At home, Radhika had acquired a routine. She helped in the house, made her own bed and breakfast each morning, and remembered to brush her teeth under occasional supervision. She had learnt to work the television and video recorder and was more adept than I at changing channels, rewinding and so on. She also worked the tape recorder and various simple kitchen gadgets. She had begun to exude an air of 'grown-upness', often bending busily over her 'writing'. Mostly this would be line upon line of rectangles, squares or circles. She was imitating me at letter writing. She could watch TV and scribble happily for hours on end, getting through reams of paper. This would distress me; I had no idea how to channel her repetitive skill into something more useful other than some similar activity such as copying from a reader.

Slowly, over a period of time, I did begin to understand her dynamics and my own. It was not possible to see that she had something constructive to do all the time. She needed to relax mentally and physically just as I did. I had to learn this, and when I could actually bring it off without feeling guilty, life was easier.

In the summer of 1985, when Aarti and Sandhya were

home on holiday, Ramesh was asked if he would like to be posted the following year to Sydney, Australia. At first it sounded too far away from India and our ageing parents. However, we were able to pay a ten-day visit to see for ourselves and to investigate the facilities for Radhika. We fell in love with Sydney, its spaciousness after Hong Kong, the weather and the whole atmosphere of the place. One Sunday visit to the open-air concerts at the famed Opera House won us over completely. The facilities for Radhika were extremely good too.

A Department of Special Education ran several schools for the mentally challenged in various suburbs of Sydney. Schools were graded according to the level of disability — mild to moderate or severe. Newcomers were tested for competency and then recommended a choice of suitable schools. We would have to live within the 'catchment area' of the school we finally chose for Radhika.

Ramesh agreed to take up this assignment the following year, so we spent the next eight months doing all the things we hadn't done in Hong Kong so far, simultaneously preparing for the move. It was yet another change for Radhika, but one we all began to look forward to. As usual, Radhika made much of this news which she shared with Mr Doherty and her friends in school. This link between home and school had been important. The daily diary introduced in the first year in Bradbury Junior School, and maintained throughout the four years of our stay in Hong Kong, provided the focal point for many conversations both in school and at home.

Radhika said she was going to miss her teacher and her friends in Hong Kong. We assured her that she would make new friends at her new school and that she would be happy before long. At least outwardly, she was convinced. Besides, Aarti had decided to transfer for a year from her college in the US to a University in Sydney and Sandhya was graduating

in May 1986, and would probably join us in Sydney till she made further plans, so fortunately and once again we were all going to be together.

In February 1986 Aarti joined her new university. On this trip to Sydney, I took Radhika for her 'assessment'. The educational psychologist was kind, but matter-of-fact. Radhika was nervous, withdrawn and uncooperative. She was graded in the mild to moderately intellectually disabled group, and we were to select an appropriate school from the list of names given. One of Ramesh's colleagues had already made enquiries and found out that the very best school for Radhika would be the Cromehurst Special School in the northern suburb of Lindfield. Bondi Special School in the eastern suburbs was also recommended.

Ramesh and I first took Radhika to the Bondi Special School. It was in session and there were about a hundred children attending. Some classes were engaged in spelling and writing, others in extra curricular activities like computer study, cooking and sewing. We had never seen so many young people in such a big programme, and were impressed not only with the near normal way in which the classes functioned, but also with the behaviour of the children and the workaday atmosphere of the school. Mr Doherty's class of five, then six children, was more like an extended family, with himself as the genial and loved father figure. He got a lot out of his children and gave them a varied education, but his class naturally did not have the same objective, business-like approach as might be expected in a larger school with more and better facilities. There were several age groups and disabilities catered for, but all in the mild to moderate category, and all were being taught at a higher standard as far as we could tell.

The next day we visited Cromehurst School set in the leafy suburb of Lindfield. It was break time. Children were everywhere — happy, bright and friendly. It looked a wonderful

place. Principal Johnson showed us round the classrooms, the library, kitchen, art room, carpentry shed, developmental room and playgrounds, finally taking us into his office. The walls were full of pictures of students at work. One poster caught my eye: "Catch them doing something right", it said. Radhika turned her back on him and fiddled with some blocks on the floor. Mr Johnson watched her. "She won't be able to sit and do nothing here", he said. "We believe that their potential is unknown. So we challenge them continuously, and find they do more and better than we expect. Our intention is to train them to take open employment and to live as independently as possible within society."

Listening to Mr Johnson, Ramesh and I realized this was just the place for Radhika. He advised us to find a home in a suburb close to the school; then they would have to give her a place, however full they were. We put her name down for April 1986. We felt exhilarated by our chat with him. He was purposeful and experienced, and the right kind to push our lazy fourteen-year-old on. As we walked to the car, we both shared our optimism and were reminded of Dina's early work with Radhika; her insistence on developmental activities as a necessary first step to learning other skills her 'Can do' philosophy rather than the 'let be' one. Now that the school had been successfully decided upon, we could pursue our house hunting with a vengeance.

On our last evening in Sydney we decided on our new home. It was just right for all our requirements, felt like 'home' at once, and best of all, was only one suburb north of the school we had selected for Radhika.

We returned to Hong Kong for final visits from family and friends in India before packing began in April. Once again Radhika saw her home dismantled, packed and shipped. Meera, our young domestic help had agreed to move with us; this would provide some continuity for Radhika, who

especially had mixed feelings about leaving her familiar life in Hong Kong. We recounted as often as we could the advantages of a bigger school and all that it offered: a common language that would make it easier for us all, the train journeys and car trips we could make from Sydney, and the fact that Aarti, and even Sandhya, would be there.

Our four-year posting in Hong Kong was now drawing to an end. It had been a challenging and very positive one for both Radhika and us. Radhika had not only adjusted to the multiracial environment of her new schools but had made progress in all aspects of the programme set out for her by the educational psychologist and her teachers.

However, her biggest achievement had been the manner in which she had handled her first menstruation and the competence she had acquired in coping with it thereafter. She had also made significant progress in both swimming and squash. Finally, through her attempts at asserting herself we ourselves had made some progress in accepting these attempts as a natural corollary to growing up, for which she did need more privacy and greater independence.

The last weeks at school were as full as ever. Doherty discussed what Radhika would find in Australia and the class put together an album of photos and messages to remind her of their time together. They bade her a fond farewell on her last day at the centre.

Radhika was fourteen in April 1986, we got her final report from Mr Doherty. In physical development he found her 'quite well coordinated.' She now liked swimming (mainly due to the intensive individual lessons from Mr Wright) and had made 'great progress.' She attended and enjoyed horse-riding lessons, most of which concentrated on correct posture and balance. She also enjoyed dancing, though not in a structured way.

Under social development and self-help skills, the report

said, "she drinks, eats, dresses, grooms and completes her toilet at acceptable levels of competency. Her relationship with adults is in the main pleasant and cooperative. There are times she tries to assert herself with other members of the group. She can be stubborn and self-willed, fortunately on very rare occasions. She has been introduced to some aspects of sex education. She has regular menstruation and will inform me why she is unable to swim. She is able to go to the toilet and do what is necessary at these times. She told me recently she did not have a boyfriend yet, but is looking. She readily blushes when teased, and can take some constructive criticism. She likes to play group games and is even more enthusiastic when she is organising others. She will wait her turn and give advice freely to others. She can play on her own and is becoming better at doing jigsaws."

Under 'life skills' she was "aware of the dangers in using a stove, kettle, toaster, iron. She can set the table, make tea or coffee unaided or supervised. She readily joins in with washing up, drying, clearing away after a meal. She finds her way around a supermarket and gathers a list of ingredients. She has shown an understanding of the dangers of crossing a road, getting on buses, trains, ferries, etc. She could learn to use a sewing machine better and knit under supervision. She has acquired all the skills necessary to use a telephone and a vacuum cleaner."

Radhika, in her mental development, was found to respond positively to instruction in class and to join in with daily or weekly activities. "There are times when she lacks initiative, and if allowed will settle for the familiar and predictable activities at the expense of the unfamiliar. She writes neatly, can type with two fingers, and scored a reading age of 7.4 and comprehension age of 6.3 on the Neale Reading Analysis. She can count to twenty without difficulty, fill in missing numbers, construct sets of numbers and complete

simple addition and subtraction using a number line or counters. She has no real concept of time. She can distinguish between dollars and cents and is able to sort small amounts of money. She readily joins in with all forms of art and craft but isn't too keen to get her hands dirty."

Conceptual learning was hard for her; the concepts of time and money were particularly difficult. Though she had progressed well, the gap in these areas was widening as expected. We were particularly happy with the effort she had made at swimming, squash, cooking and self-help skills, and told her so.

In the weeks before we left Hong Kong her *nani* was with us. The flat emptied, we moved into a hotel for the last week. Radhika and her *nani* shared a room next to ours. After all the packing, this was a most luxurious rest. Radhika loved being spoilt — beds made, rooms tidied, waiters, answering bells and providing what we wanted. She knew how the toilets, baths, phones, etc. worked, and had great fun teasing her *nani* about her ignorance. Then came the final goodbyes and the overnight flight to Sydney. It was towards the end of April 1986. Sydney was bathed in autumn sunshine and autumn colours with clear skies and open spaces. It was a relief to be out of Hong Kong!

Chapter Twelve

In Sydney, Ramesh's office was in the business district of the city, and we spent the first two months in a service apartment just five minutes up the road. The apartment overlooked the Sydney harbour bridge and several parks with a beautiful old church facing us. We were near enough to enjoy the open-air concerts Sydney is famous for, and could wander easily around the streets and parks. The weather was lovely, neither hot nor cold with clear blue skies, vistas of blue bays and white sails, trees turning to gold and bronze, and a feeling the 'Aussies' generated that life and their country was meant to be enjoyed. It didn't take us long to begin to feel the same.

Radhika was delighted to have Aarti there. Aarti brought her friends over to meet us and Radhika got to interact with them. As soon as we were more settled we decided Radhika should start at Cromehurst. She was looking forward to a regular routine again but was also apprehensive. We hired a car which I could drive and Ramesh came the first couple of times to show me the way till I felt more confident. I certainly feel afraid of new experiences and put it down to my protected childhood and youth. By comparison Sandhya and Aarti are far more experienced, particularly after all their travelling. Radhika's lack of confidence goes much deeper of course, and will always be a problem despite the exposure she has had.

That first day in Cromehurst, we took her in and introduced her to the staff on playground duty. They were expect-



Reflections.
Sydney, 1987.



Outback Australia.
Sydney, 1988.

Hunting in the Snow.
Sydney, 1989.



Moonlit Woods.
Sydney, 1989.



Gunghat.
Sydney, 1990.



Radhika at 10 months; Bombay, 1973.

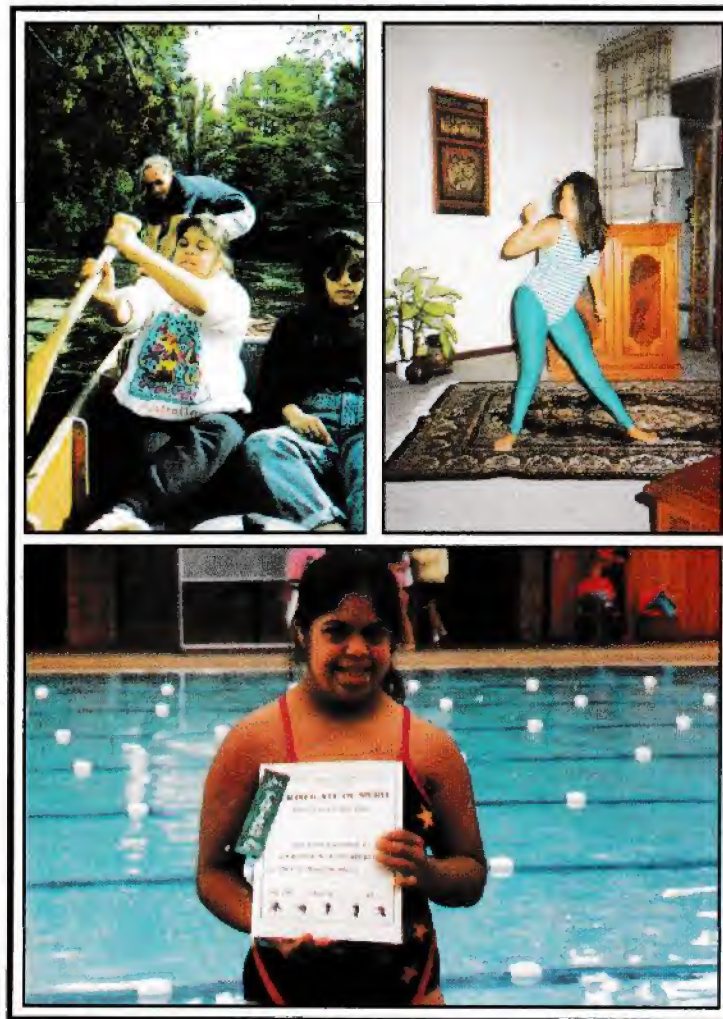


'Determined'; Dina and Radhika; Bombay, 1975.



'My old gang of friends'; Calcutta, 1980.

'The pleasures of cooking'; Radhika with Annsan; HongKong, 1984.



(top left) Rowing — Aarti, Uncle Charles and Radhika; Oxford, 1990.

(top right) Wild and Free; HongKong, 1985.

Thrilled with her first swimming success; Sydney, 1988.



Daughter and Mother; Delhi, 1996.

Radhika and Dad looking at photographs at Sandhya's; Sydney, 1991.

ing her and were friendly and welcoming. Dozens of youngsters, boys and girls of all ages, were busy enjoying themselves before the school bell rang. Radhika stood near the fence, alone and wistful. She looked the way she felt, unable to express her feelings in words. She was the last person to leave the playground and only when her class teacher came to collect her.

This aloneness continued for many weeks. It was sad to watch her, so aloof, when all the others seemed so friendly and relaxed. Then one afternoon, when I went to pick her up, I saw her walking towards me hand in hand with an older Chinese boy. Antony introduced himself and said, "She's my friend." My heart went out to him for befriending my little girl. Of all the twelve children in her class, she had found it easiest to make friends with the only Chinese boy in the school. She didn't explain why, but we knew he must have reminded her of her Chinese friends in Hong Kong.

In Hong Kong she had been one of five or six children, mostly Asian, with one teacher and one assistant teacher. As Mr Doherty was wont to say, it was like an extended family. Now she was one of a hundred and twenty children, ranging from four years to eighteen, with nearly thirty and mainly European staff.

Besides differences in sheer size and composition, lessons in Class 5 were more formal at Cromehurst than Radhika was used to. She had spelling lists to learn followed by a weekly spelling test, reading, comprehension, making and writing short sentences, number work and the weekly short story to be written at home.

From the various extra-curricular activities offered, Radhika chose sewing over grooming and very laboriously learnt a few simple stitches. Like everything, this was hard and required concentration from her and the usual patience and encouragement from the teacher. Once she learnt to hem

and stitch on buttons she would be able to do her own simple mending. Once a week children were taken on outings on public transport to familiarize them with travel procedures and to visit places of interest. For the first year Radhika 'lagged behind' on these occasions refusing to take an interest and often falling asleep on the train.

There was so much that was new and different that Radhika withdrew into her shell. She told us she liked her new school and she certainly went happily each day. However, she took several months to begin to thaw. Meanwhile her teacher tried and tried to motivate her without success. Finally at her 'wit's end' she told me that she could not get Radhika to take an interest in anything at all. When I explained how very small Radhika's school in Hong Kong had been and how she has always clammed up in new situations she seemed to appreciate Radhika's difficulty. However frustrating, we had to keep trying until Radhika felt confident enough to drop her defences and begin to participate more readily.

One afternoon a few weeks later when I was in school to collect Radhika, Mr Johnson stopped her to ask what she had learnt that day. 'Nothing much', she replied, much to my embarrassment. He looked down at her and firmly told her she must think harder, 'for in school, every day, each student learns something new.' She was being forced to think, to reply. We knew that she was in the best school for her.

In July 1986, Sydneysiders were participating in a Sports Aid walk/run to raise money for Africa. It was the usual sunny day and there were hundreds of people — old, young, toddlers and people in wheelchairs gathered in the large park. Our family, consisting of *nani*, Ramesh, Aarti, Radhika and I, bought our banners and started off. It was a two-hour walk and Radhika walked along in good form. She enjoyed participating and despite some flagging, kept going. She was

making a physical effort quite cheerfully. I sent the news to her teacher and that week she got her first class award. Her name was read out at the school assembly. Her excitement knew no bounds. Beaming from ear to ear she rushed in with the school newsletter and thrust it in front of me. "Have a look, Mummy I got the class award," she said eagerly. We were delighted and sensed an increase in her confidence at once.

The other class awards that week went to Damien in class 1 for good behaviour; Amanda for trying hard in class II; Lucy for good work and sensible behaviour in class III; and to Robert in class IV for tying his own shoe laces.

Some months later Radhika took care to produce a good story for her news book. She composed short sentences that read well, wrote them down in a neat handwriting without missing letters or words and cut and pasted two pictures from the newspaper to illustrate her composition. She got a good mark and the class award for 'making a good effort with her news book.' At last she was being jogged along very nicely, and becoming better motivated all round. Best of all, she had begun to enjoy the school and the stimulation it provided, although it took her a few more months before she got into full swing.

One of the earliest classes she had begun to enjoy was the weekly cooking lesson. Simple recipes were tried out and photocopies sent home. Her folder grew to include recipes for scones, cakes, main dishes and snacks. She loved cooking at home too. Scones were made regularly and most successfully for all our guests. Main dishes included a dreadful sounding concoction called 'sweet beef curry', though when we had steeled ourselves sufficiently to have her make it at home, we found it was pleasantly different from the usual. At school, the students took turns to do the shopping under supervision. Preparation, cooking, cleaning and clearing up

after was managed entirely by them with gradually less and less supervision. Boys and girls were given the same tasks, and enjoyed the lesson while acquiring the necessary experience to manage small meals for themselves.

However, Radhika did not like having to learn her spellings, deal with money or tell time. She was nearly fifteen and her teacher had struggled for months with little success. She found it difficult to differentiate between the vowel sounds, diphthongs etc. and only very occasionally managed a good mark in the spelling test. She spent two years in class V struggling with spelling and simple sums which were dropped, mercifully for her, when she moved up to the Extension class.

Principal Johnson's firm belief, based on years of experience, was that while society imposed limits on the abilities of the learning disabled, these limits were exceeded by a growing expectation that they could be exceeded. Cromehurst children and their achievements were living proof of this faith. It was this conviction that enthused staff and students alike and was responsible for the school's special atmosphere of cheerful positivism.

We tried to practise the same approach at home. Usually Radhika responded well and pleased us and herself, but whenever we approached her negatively, her reaction was also negative and contrary. It has not been easy for us to change our approach and we have had to consciously remind each other how whenever we have managed to be positive with her, our success has been her success as well.

The teachers had a sensitive understanding of the need of special children, without giving in to sentimentality or over-protection. Knowing their individual weaknesses but relying on their strengths, the staff were able to get the best out of them. Students were encouraged in a wide variety of activities, and given responsibilities which they were expected to fulfil. Discipline was integral to the whole, but maintained

without recourse to harshness and without belittling the self-image.

Since students were expected to do the right thing and were always appreciated for doing it, they generally did. However, when they didn't, disapproval was made quite clear verbally, or by being made to stand outside the class. For a more serious offence the child was warned that he would have to be sent to the Principal's office. Often this warning was deterrent enough. When it wasn't, the child was actually taken to Mr Johnson. After a talking to, he would have to stand outside the office where everyone could see him. This was the ultimate disgrace, and usually solved the problem.

Radhika has always behaved better in school than at home. The approval of her teachers has been very important to her. While she always remembered to tell us who had misbehaved and who was punished or sent to Mr Johnson's office, never once did she admit that she had been disciplined; in fact she said she never did anything wrong!

Parents were encouraged to participate in school activities. When the need arose, we could meet the principal or Radhika's teachers at any time. Always willing to help, we found their concern palpable and their advice sound. Never were we made to feel at cross purposes with them. In fact their openness and trust encouraged ours and served to re-iterate our common goal.

Cromehurst was altogether a quite remarkable school with an exceptionally progressive principal and a very dedicated staff. What amazed me then, as now, is that it was a government-run school. We were fortunate indeed to have Radhika benefit from four years in such an institution.

During this unusually long period of settling into her new school, the familiarity and security of her own home would have helped. However, we were in the Service Apartment for nearly three months before moving to our house in July 1986.

The container of luggage had arrived from Hong Kong, and though much renovation and upgrading was still to be done, we moved out of York Apartments in the city to Eastgate Avenue, in Killara. Radhika was very happy to open the packages and put out the familiar things and finally have a settled home again.

The local Kuringai Council had a booklet of invaluable advice. Paper, bottles and cans were collected every two weeks for recycling. "What's that?", asked Radhika. Once she understood, she helped save, collect and carry old papers, empty cans and bottles down to the front gate from where they were collected by the council. It was her job to empty the kitchen trash every night, tie up the plastic bag and dump it in the drum outside the kitchen window.

In the evenings the milk van would 'moo' its arrival. Radhika would take the empty bottles in a crate down to the road, exchange them and have a chat with the driver and the two young neighbourhood boys who helped him with the deliveries. Thus each of us gradually began to settle in, getting to know the routines, the local shops and faces. It was a quiet neighbourhood despite the many young children and the adults who kept mostly to themselves.

We were pleasantly surprised when nine-year-old Samantha visited us one Sunday morning and welcomed Radhika to the neighbourhood. It was a heartwarming gesture, and we asked her to join us for an Indian lunch. Radhika was shy and quiet, but we could tell she was pleased. Samantha had two younger brothers, six and five, and once in a while all three would visit. In the early weeks this was very welcome. Once I found Radhika and one of the boys were not downstairs. I panicked and ran upstairs. Her bedroom door was shut. I opened it as casually as I could and found them sitting, playing with a train set. If Radhika had been overfriendly, she looked quite innocent now.

However, my anxiety was overwhelming. Her growing interest in the opposite sex and her lack of discrimination was a worry and I felt totally responsible for her behaviour. Why had she shut the door? Had she tried to kiss or cuddle the little boy? What would he tell his parents and what would they think of her and us? Should I go across and explain Radhika's disability? Should I assume she had gone beyond the bounds of propriety, warn them, and risk warning them off altogether? For days I could think of little else. I asked her several times if she had tried kissing him, and each time she said no.

After the first few months Samantha and her brothers stopped coming over. Radhika made new friends in school and exchanges of visits followed. But Samantha and her family remained friendly whenever we ran into one another, so we decided that nothing untoward had happened. This area of Radhika's interaction, especially with her younger peers, has been an extremely nerve-racking one for me as I cannot bear to think she may do something to discredit herself in the eyes of others, or make us ashamed of her. Ramesh and I explained this to her as best we could, and continued to watch her closely when she was with younger children.

Meanwhile Sandhya had graduated with honours from her college in the United States and was now expected home. There was tremendous excitement as the three sisters were going to be together again and *nani* was still with us. The house was being renovated and repainted, furniture and furnishings were being delivered, and we had a full house. Ramesh had a small swimming pool put in and the rather overgrown garden was gradually cleared and maintained by Tony, who became a good friend over the years. We learnt that he gave gardening lessons to the mentally handicapped, and although Radhika never got interested in gardening, she enjoyed chatting with him and he with her. He admired her

paintings, enjoyed her ease and affability and was touched by her concern for the scratches he suffered from his gardening.

Redecorating and furnishing the entire house while there were so many of us living in it had been an exhausting business. In October 1986 Ramesh insisted I should visit Delhi and Chandigarh for a two-week break. He was going to be in Sydney and was willing to manage office, home and Radhika. While I was away, Ramesh met Danielle's parents at a school function and broke the ice by inviting Danielle to spend an evening with Radhika. It was the very first time she'd had a friend over from her new school. They watched TV together, played Ludo and other games and then Ramesh took them to the Pizza Hut for dinner. It was a great success for both girls and became a regular feature. Ramesh has invariably organized such occasions from time to time thus ensuring that Radhika is happily occupied. He manages all this in a natural, matter-of-fact way, the result being that father and daughter get along well and enjoy their time together. Knowing this I have been able to leave them for short and necessary breaks.

On my return from India we finally got the opportunity to explore Sydney and its beautiful parks. Our friends told us we could go out every weekend to a different one and not exhaust them for years. So we bought ourselves a picnic basket and began to do just that. Sandhya had left for a job in Hong Kong but Aarti and her friends joined us whenever they could and Radhika especially loved their lively company. Very soon they got used to her, happily including her in their banter and games. She was fortunate in having the stimulation of so many young people and no doubt they too learnt to be easy and natural in the company of a youngster with a disability.

As the winter turned to spring and summer, indoor games gave way to outdoor activity. Swimming and badminton, table

tennis and frisbee provided good exercise and coordination practice for Radhika. It was good that she had learnt to play as many games as she had as these were excellent leisure activities for the family as a whole.

It is interesting to recall that every teacher from Dina onwards had encouraged us to teach Radhika various games. Starting with snakes and ladders and simple card games, and moving on to pelmanism which tests the memory, UNO, Adlib and Boggle, Trivial Pursuit, Draughts, Carrom and even Scrabble, Radhika learnt the rules and became quite clever at some of them. She certainly managed to keep up in most, and enjoyed them thoroughly. Practice improved her skills, except at Carrom for her short, stubby fingers lacked the strength and dexterity to flick the counters. Lack of success meant no desire to play. She would not even try. Scrabble was hard because her spelling was poor. So we played Children's Scrabble until she outgrew it.

Towards the end of 1986 when she was better acquainted with the school routines, her teachers and fellow students, she felt confident enough to try harder without worrying too much about failing. We have learnt to expect diffidence and lack of motivation from her. However, on the few occasions she has shown initiative, for instance wanting piano lessons, we have quickly and happily fallen in with her suggestion, so as to boost her self-confidence.

Radhika loves the 'beats' and rhythms of modern pop music. From an early age, she has responded well to music. She would put on her leotards, loosen her hair from the usual pony-tail, and dance energetically, totally absorbed. A good outlet for her energy, it allowed her to express herself freely, without fear of doing 'the wrong thing'. She was a delight to watch — her body light and graceful, her movements flowing with the music and her abandon complete. She still loved an audience and approval. Most times this was a plea-

sure, but as she grew older I sometimes found myself unwilling to respond with the expected applause. Would I have to applaud and encourage always? Is her need to be praised a sign of her continuing low self-esteem, or a childishness that will take longer to outgrow? Have we indulged her with too much praise? As she became more accomplished, it began to dawn on me that our relationship too would have to become more natural. Since we have to praise our children more than normal, we must also remember to be firm when necessary.

She still loves music and dancing but no longer needs us to watch her. She dances in her own bedroom with the door shut, and we have to cajole her to dance for us when we want to watch. She has known how to operate her music system for many years now and has her favourite tapes for dancing. She knows what she likes in music, as in food and clothes. She knows what she wants to do and what she doesn't and has a very definite taste in these areas.

Towards the end of the year we were settled well enough to think of a pet for Radhika. Many of her Australian friends had pets at home and now she too began to ask for one. She had wanted a dog in Hong Kong but not wanting to raise a pup in a flat I had refused. Now that we had a big house and garden, I was keen to get her one. Ramesh and Sandhya don't like dogs, and Ramesh did not want the burden of looking after it to fall solely on me. Sandhya felt, as did Aarti and I, that a pet would be good for Radhika and we finally managed to convince him. It could not be arranged in time for Christmas, but we began looking at advertisements, located a breeder of Labradors and drove down to choose one. Radhika was sure she wanted a 'black female Labrador pup'. There were two black females left and she finally decided on the smaller one, the runt, who grew and grew until we had to call her our baby buffalo.

The pup was six weeks old when we collected her, in time

for Radhika's fifteenth birthday. We tied her up in red ribbons and put her in Radhika's arms. She was nervous. The puppy was frisky and Radhika didn't know what to do with her. It took weeks before she learnt how to play with the pup, and what to expect from her. Radhika decided to call her Cindy, so Cindy she was.

Radhika's school friend Arni had had a dog of her own for several years, and obviously had some experience in training it, so Arni came over for weekends and helped Radhika get started. Cindy was put on a long leash and Arni would tell her to 'sit', 'stop', 'come' and so on. At first Radhika would speak to Cindy in long sentences and could not modulate her voice to be gentle and yet firm. Arni enjoyed teaching Radhika. When they could get Cindy to obey, they would lavish her with praise and give her a biscuit as reward. Radhika did not want me to interfere, and to prevent myself from doing so, I would watch them from the kitchen window. Now when Radhika's friends came over, they had Cindy to play with, train, feed, brush and occasionally bathe.

At four months Cindy was a delight for everyone but, despite Arni's best efforts, not yet fully trained. Radhika's class teacher suggested that Radhika and I take her to Obedience classes. These were held in Lindfield park twice a week for an hour during school hours. Mrs White was happy to let me take Radhika away as she considered this to be excellent training for Radhika and Cindy. It looked like a picnic for dogs and owners with their water bowls and flasks of coffee but turned very serious when both were put through their paces by the professional trainers. Cindy, big and still very frisky, would pull Radhika around if she didn't want to obey. Unnerved, Radhika would yank the leash too hard and shout at her to little avail. Radhika who was the only person with a handicap at these classes needed the extra help she got from the trainer. Gradually she learnt single word commands,

how to make Cindy obey and when to pat approval. "Radhika, do you see why obedience is necessary?", I would ask, "When a dog is obedient and disciplined, life is ordered and easier for everyone."

Although she liked routines she did not like being disciplined herself. Therefore this concrete experience with Cindy was extremely valuable. Slowly but surely Radhika began to get the hang of teaching Cindy correctly. She practised at home and when she succeeded, couldn't resist giving her dog a hug and a biscuit. Cindy would wag her fat tail much to Radhika's delight.

Apart from learning the value of discipline there was a host of new words connected with rearing a pet, so Radhika's vocabulary got another boost; and with the amount of actual work to be done for Cindy she had to acquire a sense of responsibility herself towards her pet.

Like all labradors, Cindy was monstrously greedy. She attacked garbage bins on Wednesdays, milk bottles left at other people's front gates, cat food from the backyard of the house in the rear, and goldfish from another neighbour's pond. She was good-looking and extremely friendly but her greed got her and us into embarrassing situations with our neighbours. Ramesh had taught her to 'fetch' our newspaper from the front gate. Not only did she do this, but on weekends we would find she had brought up two or three others as well. We couldn't tell whose papers she had picked up, until one irate gentlemen rang to inform us that 'our dog had taken his newspaper'. Such escapades gave us food for thought and family discussion, while giving Radhika plenty of stories to tell in school and write about in her Newsbook.

At fifteen Radhika was expectedly short, with a small head, short stubby hands and feet, slack muscle tone, and mental impairment, all associated with Down's Syndrome. However, with the critical and rigorous early training and continuing

stimulation she was by now able to approach if not actually enter that realm called 'normal' we had longed for and worked so hard towards.

She was pleasing to look at with soft warm eyes, a ready and engaging smile, near normal gait, often lively and witty, almost clear speech and an ability to communicate reasonably well. What is more, she was never clumsy or embarrassing. Although she still struggled with simple spelling, reading and numbers, she was learning to use public transport and libraries, play various games, cook and use households gadgets and interact in the adult world.

However, not so long ago children with Down's were regarded as 'severely retarded'. Raised in unspeakable neglect they lived to an average age of twenty and died, often without so much as learning to speak. This was my nightmare. Today, we know that most Down's Syndrome children fall into the 'mild to moderate' range of retardation and have 'as yet unimagined and unrealized potential'.

According to the March 1988 *Newsweek* article entitled "Waking Sleeping Souls", this revolution in the US was led by parents in the sixties who 'rebelled at surrendering their children to institutions that were near neighbours to dungeons'. It was only in the seventies, with the maturing of the first generation raised at home that their potential became clearer. Dina brought this new awareness from the US, and we were the beneficiaries when she began to work with Radhika in 1974.

Goals for children with Down's Syndrome always have to be simple and realistic. On the verge of entering adult life if Radhika could be trained to live in a supervised group home, helping with cooking and housework, and have a small job during the day this would be a realistic goal for her. Very modest expectation, except by comparison to what her fate might have been had we not found the indomitable Dina and

now Cromehurst whose entire programme based on their 'unimagined and unrealized potential' had the very same goals.

Chapter Thirteen

In April 1987 we discovered with shock that Ramesh needed an angiography. This would mean two days in hospital, and despite the cardiologist's assurances, I was extremely apprehensive. Sandhya was working with a bank in Hong Kong and could not get leave to be with us. Aarti was at the university in Sydney and spent those days at home. Radhika was included in most family discussions, and although I tried not to convey my anxiety to her, she felt our concern and carried the news to school. Once she had told her teachers, they arranged for her to spend time at the cottage with her friends so I could concentrate on Ramesh. Their help was invariably practical and often the result of Radhika's 'First Information Report', so to speak.

The angiography went off successfully, but it confirmed the need for open-heart surgery as three arteries were blocked. Ramesh felt certain he would prefer the operation to long-term homeopathic treatment. It was a major dilemma for me but eventually I accepted his wishes. The surgeon told us we could wait up to six months for the operation and choose a convenient date. It was fixed for early November.

In the intervening six months we lived as normally as we could. Radhika was as good as gold in school. At home she watched too much television, resented interference and often didn't do the tasks that she was responsible for. It was her job to make her bed, her own breakfast and school lunch and this she did without fail. But when it came to giving Cindy

her milk and meal, a brush and walk, she had to be constantly reminded and coaxed.

Setting the dinner table each evening was also Radhika's duty. This she could do quite competently. However, if she was engrossed in a TV programme, she would resent the interruption. On one such occasion, she lost her temper, shouted and stomped out, banging the door behind her. As I began to set the table myself Sandhya stopped me, saying that Radhika should not be allowed to get away with such behaviour. She insisted that Radhika come down and do her job. This was a sensible intervention on Sandhya's part. It was right to get her to do her share; she should not feel that a show of temper and flouncing out of the room could rid her of her responsibilities. She was becoming smart enough to take advantage if given a chance.

Radhika resented my telling her off. She responded better to her sisters with whom she got on well and shared a few common interests. With Sandhya she would cook the occasional cake or snack, and watch L.A. Law, a TV serial they both enjoyed. She looked up to Sandhya at this stage, listened to her and even took her dieting and exercising seriously when Sandhya was around to goad her on. With Aarti she had a more equal relationship. Aarti helped her with her knitting or embroidery, and also enjoyed discussing the weekly story for her newsbook, getting Radhika to frame short, simple sentences and write them down coherently.

The relationship between them has seen many changes since Radhika's early years. When she was physically fragile and had no self-confidence, they were extremely gentle and protective. As she grew stronger and acquired skills that increased her confidence, they became less protective towards her. Then when she began to blossom in Cromehurst, they began to tease and even be quite rough with her. Although Radhika has never liked Sandhya's merciless teasing, she is

now able to take it without loss to her self-confidence. All three thrive on this healthier relationship.

Ramesh has felt I tend to overprotect her; by jumping to her defence I have not allowed him to deal with her directly, or in his own way. This is true. I have felt I know her and understand her best, and that 'my way' is better than his. After all I have spent more time than him, with her and her teachers. But it goes much deeper really. My need to protect her is a ferociously instinctive one: to protect the most vulnerable offspring I have, in the manner I think best. Is this solely a maternal instinct, or do I still feel guilty for having given birth to her, and therefore feel entirely responsible for her?

One suggestion that she be taught domestic chores so that she was a help to whoever she lived with was instantly dismissed by me, even though it came from my own mother. My daughter was not going to be a 'help' in the house without a meaningful life of her own. She must of course learn to cook, clean and wash, but not only that. I wanted more for her — at least as full a life as she could have under the circumstances — a job outside the house, friends and some social life. This seemed distinctly possible.

I have protected her from what I felt was unfair criticism or insensitivity, even when it came from the immediate family. By seventeen or so she had begun to look upon me as her 'ally'. For many years she had been mimicking my tone of voice and mannerisms, then my opinions, and of late, in discussions with Ramesh she began invariably to take my side. No matter what the subject, very soon she would say to her father "Mummy is right", and "Yes, Daddy is wrong." Ramesh started calling her Mummy's 'dum'. This caused amusement all round, especially as she so readily accepted being 'Mummy's dum'. However, it made me realize just how much and how easily I did influence her. I wonder if she subconsciously feels my hurt and this is her instinctive way of

compensating me.

Although I have been supportive and understanding of Sandhya and Aarti, I have never felt as protective of them as I have of Radhika. Ramesh brought it up only recently. I presume he felt I was able to accept it without falling apart myself or chewing his head off for making such an allegation. He is more objective about her than I have ever been able to be. He says he accepted her condition without feeling any guilt, whereas, he thinks I am burdened with guilt which has made my relationship subjective and often fraught with difficulties.

Yes, I have been burdened with guilt from the very beginning. In the early years I was able to suppress it by putting all my energies into teaching her everything she needed to learn. When occasionally it surfaced, I would rationalize, justify and soon cover it up. But all along I have felt Radhika is my sole responsibility, my personal cross to bear, not Ramesh's and certainly not Sandhya's or Aarti's. Driven to struggle on my own, unable to acknowledge Ramesh's tremendous contribution and afraid of facing my deepest hurt, I have clung to the belief she is 'nearly normal'. Unable to accept the truth myself, I have been unable to admit it to others. Is she that 'idiot' of my nightmare, with vacant look, drooling mouth, tongue lolling, who can only sit and stare? No, my mind screams. No, my daughter is not that. I have seen to it she is not. I have striven all these years to ensure she is not. And the sober truth is that she is not that 'idiot' of my nightmare. She is, however, intellectually subnormal — she will never be able to live independently, earn a living wage, manage her finances, raise children or do the hundreds of things 'normal' people do. Finally, after twenty years of struggling against it, I have come to admit her subnormality and in the words of T.S. Eliot "arrive where I started and know the place for the first time."

At the end of her first year in Cromehurst, Radhika's class V teacher told us she now needed to be 'travel trained', and that I must do this to increase her independence and confidence. First, I myself had to learn exactly what was involved. I had to take her to the railway station at Killara, show her the two announcement boards for citybound and northbound trains, help her to read whether the next train was stopping at Lindfield Station, and then to check the clock to see when the next train was coming. She had to be shown that when the train stopped and the doors opened, alighting passengers should be let off first, then she could get in, and find a seat where there were other passengers, and not in an empty coach. Lindfield was the very next station on the citybound line, so she had to be prepared to alight. We did this together both ways everyday for a week.

Now, her teacher said, take the same train but sit in different compartments. Radhika got on, and then I did. "Don't forget to get off at Lindfield", I told her. At Lindfield I got off and walked to her door. She was inside, waiting. There had been a few people getting on so she had not been able to get off. Just then the whistle blew. I panicked, and got her to jump out of the train as it slowly moved away. "My heart is bumping hard", she said. My own had stood quite still. I explained again that passengers getting off have right of way, and must do so quickly before people start entering.

After a week of this second stage of travel training, I would drive her to Killara station, watch from the road to see she had got on, then drive to Lindfield and wait for her to come out, cross the road when the green light came on for pedestrians, and then walk her down the road to the school. Once she was confident, and I was sure she could manage, we let her travel entirely on her own. The school was aware she was new at this and kept an eye on her safe arrival, and since trains ran to a fairly reliable schedule, we knew when to expect her

after school. We were too far from Killara station for her to walk home, so she was dropped and picked up every day from the Killara Post Office, opposite Killara station.

Radhika was fourteen years and nine months at this point, and the simple, step-by-step instruction she received showed how far behind normal she in fact was. Yet she did have the capacity to learn and had gradually built up the confidence to travel on her own. Travelling independently like her schoolmates and other fourteen year olds was a great morale booster generally. She felt more able to handle other aspects of her life and began to exude a very fetching brightness and self-confidence. We had had no idea how beneficial this would be for her. I had been unduly nervous and hesitant to let her even start the training. Had her teacher not pushed me into it, Radhika would have been denied the experience and remained timid, thus widening the gap rather than closing it.

In a similar way Radhika was taught to use public telephones. A normal person does these things automatically, reading and understanding instructions on the instrument. For Radhika, I had to read them out, telling and showing what she must do at each step. She was diffident at first but once she had done it several times with me standing near her, she was confident enough to occasionally call her father at office or me at home.

Weeks after she had become an independent traveller, I happened to be at her school. Her teacher informed me that one day she had been late getting to school. The staff waited, before calling me, when she turned up. She had got on to a fast train that didn't stop at Lindfield. When it did at the next station, she crossed to the other platform, waited for the next train, got off at Lindfield and walked to school. They were very pleased with her, and so were we. Obviously she had known what to do and hadn't been afraid. Having ex-

plained her late arrival to her teacher, she didn't think it necessary to tell us. Her growing confidence, independence and competence were a source of comfort and pride, both to herself and to us.

On a couple of occasions she didn't come off the expected train at Killara. Once she was found in the school playground with friends. Another time she wasn't to be found anywhere in school — and nowhere near Killara station. We were frantic, and having spent an hour looking for her, I drove to the nearest police station, and requested their help. They listened but were not too fussed, saying I should let them know when she got home. She had been expected at three-fifteen pm and it was nearly six pm when she was found near our home. She had walked all the way from Cromehurst — not lost her way — safely crossed several very busy roads. When we asked her why she had not taken the usual train, she explained that it had been 'full of children' and she couldn't board it. She was hot and tired, but had a friend's birthday to celebrate that evening. Arni was picking her up in less than an hour to see the musical. 'Les Miserables'.

We have tried to close as many gaps between her and her normal peers and have succeeded beyond our expectations. However, the basic gap in intelligence exists and will do so always. When it shows up, it hurts me deeply although her many accomplishments make it bearable. She is extremely sensitive to her own inadequacies. She does, however, thrive on being treated normally, as long as we make the necessary allowance for her slowness in grasping and reacting, and do not undermine by word or look her always fragile ego.

Radhika was now comfortably settled, fully occupied and responding well to all the stimulation she was receiving, in and out of Cromehurst. At last, we could sit back and enjoy without the ceaseless anxiety to ensure Radhika was getting all she needed. I had time to relax, time and freedom to

develop my interest in Homoeopathy. I joined evening classes, read and studied, made my own friends and felt quite free from guilt as I knew she was well taken care of. While she bloomed under our very eyes, I struggled to learn anatomy, physiology, symptomatology, diagnosis, and homoeopathic principles and practice. She seemed to like the fact of her mother attending classes and giving tests, 'struggling' like she was at her spellings etc. to concentrate and memorize.

Now I was better able to understand what Aarti was doing in her study of genetics, and we had some enjoyable evenings sharing our interest in the human body. One day, while we were discussing how various organs work, Radhika let fall that we breathe through our lungs. Surprised, we asked her how she knew. "Oh, we have a male model in our classroom", she said. "It has removable parts, so we talk about them, remove them, mix them up and then put them back again." "How very interesting, Radhika, but why have you not told us before?" asked Aarti. Radhika smiled and kept quiet. Here was another subject to share with her. Soon after this the family watched a TV serial called 'The Living Body'. Extremely well done, it was simple enough for even Radhika to take a lively interest.

As for me, I loved every moment of my three-year course and was grateful for the chance to take it on. Ramesh encouraged me all through and took pride in my achievement. These were proving to be extremely fulfilling years for all of us. It is no wonder we were able to relegate her 'subnormality' to the back of our willing minds and enjoy a period of well-being and rest. This is not to say we had no worries at all or that we couldn't see the fateful gaps widen in some areas.

In December 1986 we received Radhika's first annual report. The principal stressed the two major thrusts of their work with her. First, to determine "in what way the child's development is not adequate and to attempt to accelerate the

development in the areas requiring attention." Secondly, "to teach those things we all need if we are to operate successfully in the adult world." Travelling independently had made her more confident and it was hoped she would be less timid next year. Her expressive language was 'excellent', although she was 'still very reluctant to express herself in public.' During excursions she was more alert and did not trail behind. Despite slow progress serious problems remained with comprehension, spellings, number work, telling time etc. The developmental teacher reported that she was 'beginning to apply herself' now, and was consequently making 'significant progress in some areas.' She was 'very astute', and good progress was expected of her in the following year. Recommendations for home included the usual — getting her to use a sewing machine, reinforcing road safety rules, independent shopping, using a digital watch and lots of jigsaw puzzles.

Her problems with spellings and numbers were due to mental impairment associated with Down's Syndrome and no matter how hard she tried they have remained to this day. While this has restricted her ability in almost all areas of life she has, through sheer perseverance, learnt to do many other things that are both necessary and enjoyable.

When there were problems, as of course there were, we had immediate recourse to her school. They had sound advice for us and dealt directly with Radhika in school. There were several such occasions in our four-year stay but two of them stand out in my memory.

The first was when Danielle had come over to spend a weekend with Radhika. All went well until after dinner when the two girls went up to sleep in Radhika's bedroom. Ramesh, his mother who was visiting at the time, and I were still at the kitchen table when a distraught Danielle came to tell us Radhika was not letting her sleep. She said she had tried explaining she was tired and wanted to sleep but Radhika was

not letting her do so. I went up without in the least expecting what I was in for. Radhika was furious at my interference and would not listen. Finally, I told Danielle she would have to sleep in another room. This incensed Radhika. She shouted angrily at me, slapped me hard on my face and pushed me against the cupboard. I stood stunned and smarting. Radhika stared surprised at herself while Danielle kept repeating "You shouldn't have hit your mother." I came down to tell Ramesh who then went up to settle matters between them. He was able to send Danielle off to the next room and lovingly quietened Radhika before joining me downstairs and doing the same for me with extraordinary love and understanding. Shocked and stunned I simply could not believe how this child of mine, reared with so much love and pain, could have turned on me with such savage fury. She would have to go to boarding school, I kept thinking and saying. This was the first and only thought in my head; so appalled was I by her strength and frenzy and my own helplessness in the face of her uncontrolled violence. We sat and discussed it for a while, deciding that night before we retired to an uneasy sleep, that the school must be informed and their advice sought.

Next day Mr Johnson listened carefully to every detail I had to tell him. He then explained gently that I must always avoid confrontation and adult explanations when she was being unreasonable. At such times, he advised, I should voice my disapproval firmly and leave her room at once. Both he and her class teacher said they would talk to her as well as discipline her in school and that meanwhile I should remain cool and distant at home. It took me several weeks to get over my shock and hurt before I began to feel normal towards her.

She was not violent again although occasionally she did sulk or shout and bang doors. Whatever the cause of her anger, the disapproval of the school authorities and the very fact that 'they' knew of her bad behaviour at home, helped

to prevent her from being violent again. Thus the only time I felt I would have to send her 'away' passed into memory and both she and I were spared that fate.

I was able to avoid confronting her during an outburst, and ignoring her at such times, continued to work. Very quickly she would look contrite and miserable, but never managed to apologize in words. This annoyed me until I learnt to accept that 'looking and feeling', rather than 'saying' sorry was her way.

The second major problem we faced was with her growing sexuality which, to our knowledge, surfaced on two occasions. The first time I was away in India. Aarti had dropped Radhika off at a school dance. These were very special occasions, much looked forward to. At ten-thirty pm when Aarti picked Radhika up she noticed that Radhika didn't look as happy as she usually did after such an evening. On asking, Radhika told her that a young boy from her class had pulled her out of the hall and got her to undress behind a tree. Taken aback, Aarti returned to find out from the teachers on duty that the two children had evidently slipped out unnoticed, were missed soon after and discovered in the dark outside with some clothes off. Aarti was assured that 'no more than a little exploration' had been possible.

A letter from Mr. Johnson was awaiting my return. Both had been taken to task since it was felt it could not have happened without mutual interest and agreement. I was assured, like Aarti that 'only a little exploration' had been possible. Radhika had shown interest in this young man and he in her, calling her 'my princess' and even telling me this when once he was invited to the house for a swim. So now here we were at this next and very important step. Radhika was sixteen and natural instincts were surfacing. The possibility of a willing Radhika experimenting with sex without realizing the consequences was unnerving and demanded

urgent attention. While we were still wondering how best to handle this new development, Radhika indulged in another bout of 'exploration' with the same boy.

One afternoon, not long after the first incident, she came home from school rather flustered, sat herself on my bed where I was resting peacefully and said, "Something bad happened Ma." I sat up but tried to remain calm. They had taken the train together, he got off with her at Killara, took her into the ladies toilet, where he once again took off his own clothes and "made me take off mine." Stay calm, ask your questions quietly, I had to repeat to myself. Then what happened? Then what? "Did he actually put his penis into your vagina?" "No," she answered. But how could I be sure? "I'm so glad you came home and told me everything," I said, my mind racing. She had a good shower and I hugged her and said she must know this was very wrong.

Next day I went to meet her principal. He felt both young people were highly sexed and attracted to each other, but 'probably hadn't gone the whole way.' He would speak with them and find out more. Meanwhile he advised us to work out what was unacceptable to our family and then convey it to Radhika in no uncertain terms. He agreed that general standards of sexual behaviour in public, and on television in a permissive society didn't help matters at all. Besides, we knew that most teenagers are full of romantic notions and desires, which the more daring ones experiment with, without watchful parents ever coming to know. Our youngsters have all the natural instincts but not enough guile to be discreet and probably do not know how far they can go. We believed that what is natural is right but only at the correct time and place. Was Radhika likely to know the correct time and place? Would Radhika know how far she could safely go, and when and how she must stop herself? Did she realize she could become pregnant, that babies were difficult to carry, give birth

to, rear? That in her case, the chances of her having a baby with Down's Syndrome were more than fifty per cent. For days and days I discussed it with Ramesh, Sandhya and Aarti and wondered how best to put it across to her, simply and clearly, without causing confusion in her mind.

Finally I had it worked out. Years ago I had discussed sex and the facts of life with Sandhya and then Aarti; now I was ready to do so with Radhika. The home had a formal sitting room in which Radhika knew that serious talks between us and the girls were held, so I decided to talk with her there. I asked her to come in when she was ready, since I wanted to talk 'very seriously' with her. She came and sat near me; she looked and behaved like a young lady. I decided I would talk to her straight, and in an adult manner. I asked her to listen very carefully as this was important. She had been right in coming home and telling me the truth at once. I appreciated her honesty and frankness. However, neither her father, nor her mother approved of such behaviour. We had not allowed Sandhya or Aarti to behave this way; we did not expose ourselves in this manner, nor must she.

She listened surprisingly attentively. Then I explained how she was now at an age when she was capable of getting pregnant, and what a long and difficult process pregnancy was. She disliked hospitals and doctors and could not bear pain; and childbirth was painful. If she got pregnant, she would have to go to a hospital and undergo a painful abortion. Her attention never strayed; she seemed to be absorbing everything I had to say. I was well satisfied with the talk. She said she had understood, so we exchanged a hug and I told her she had been 'grown up' and that I was proud of her.

I know it went well. I was particularly pleased with her seriousness and attention. But would she remember at the time if, on some future occasion, she was drawn by instinct to explore? I could never be sure. Certainly she never told

me anything like this again, nor was she found in such a situation in her school. Her teachers had general discussions on this and related issues with their students. The school knew what I had told her and how ably she had responded, and I knew what arrangements they had made to keep these two apart. He was only allowed to catch the next train after her. Radhika's adult response to my earnest and sober talk was definitely the result of the adult treatment of the youngsters at school, and of our efforts at home to refrain from treating her like a child. She was a 'young adult', she told us. It was something to build on.

In the light of these worrying incidents, both school and family felt we must take steps to safeguard her against unwanted pregnancy. The Principal introduced us to the gynaecologist at the Royal North Shore Hospital, and we took Radhika to meet her. She was a sensible woman, large with child. Radhika looked at her and said, 'Oh dear!' "You don't want to look like me," she asked Radhika quickly, "Do you? We shall give you some pills which will ensure you don't." Radhika took to her, had a chat, and agreed to take the pills.

The graded contraceptive pills had to be taken every night in serial order. This was supervised for months, but slowly Radhika was learning which pill came next. Then one night she made a mistake. The lady doctor was not available, being on long maternity leave. The nurse on duty gave me advice I didn't think was right. I rang Aarti, who rang a Family Planning Clinic. They couldn't advise what to do or how to rectify the mistake, except to say she could stop having the pill until she had another period and then start again. I did not think it wise to risk this happening again and again, nor were we sure we could sustain the close supervision needed on a daily, long term basis, let alone the possible side effects which we were not even considering at the time.

After more family discussion, we consulted the school

again and took Radhika to another doctor in the nearby suburb of Hornsby. He felt we should get a full hysterectomy done and be rid of the problem once and for all. We explained Radhika's difficulty with anaesthesia, so he decided to change the pill and said we should come back later. With the first series of pills Radhika had put on weight and her face had been covered with a rash; we wondered what the side effects of this second pill might be.

My study of homoeopathy proved extremely worthwhile in understanding how intricately the human body works, how completely interdependent all functions and systems are, and how good health is a harmonious balance at all levels. A hysterectomy at such a young age would, I felt sure, lead to other imbalances and problems. Besides, while Radhika did not enjoy having her period, she had certainly learnt to cope well enough with its requirements. I also knew she did not respond at all well to anaesthetic of which she would need a heavy dose for major surgery. All things considered, we felt a tubal ligation requiring less anaesthetic would be less disruptive of her hormonal systems, and therefore the best way to go.

However the school informed me about the difficulties parents were encountering with the interference from a 'do gooding' group that wanted the young person to make such decisions for herself. It did not matter what the handicap was, how difficult the period might be, or how necessary it was to avoid pregnancy. The government of New South Wales had constituted a Guardianship Board to deal with such cases and parents would now have to present their case to the board whose decision would be final.

All we wanted for Radhika was a tubal ligation. This was not an easy decision, knowing her response to even a small dose of anaesthetic, considering her phobia of doctors and hospitals, her terrible fear of pain, and her natural but high

libido, we felt we simply had to go through with this to ensure her safety from pregnancy. We were equally sure she must not ever have a child because there was no way she could responsibly bring it up; and should it have Down's Syndrome, it would be quite impossible for her and for us. As our entire thrust has been to provide her with as normal a life as possible, a tubal ligation would allow her the freedom to develop a normal relationship without fear of pregnancy. The gynaecologist understood and agreed. We filled in the required forms, and felt sure there would be no difficulty in getting the Board's approval.

A month later we were informed of the date and time of the hearing. The school sent Mr Oliver, Radhika's extension class teacher and Mrs Duncan, the cottage coordinator to represent Cromehurst and support our case. Both knew her well. We took Sandhya and Aarti along with Radhika. We were ushered into a large room, furnished with a vast, intimidating conference table with chairs around it. Radhika and her 'supporting team' sat on one side and the four members of the board sat opposite. They introduced themselves by name and profession. Only then did we realize they had a lawyer to lead their team. Ramesh realized earlier than I, that they also had a tape recorder switched on behind them. The entire proceedings were loaded against us from the start. They asked us to explain our position. It was utterly shocking to have to talk (and weep) about Radhika and her little forays and inabilities right in front of her. It was the worst hour and a half of humiliation any of us had ever been through on her account. Each of the family spoke in turn, justifying the simple ligation for Radhika. Then Mr Oliver and Mrs Duncan were asked to give their opinion. Next, the board wanted their counsellor to speak with Radhika alone, so we all had to leave the room. Radhika remained with her for nearly half an hour. We don't know what she was asked or what Radhika

said in reply. Then we waited outside for an hour while they deliberated their decision.

Finally we were called in with Radhika to hear their 'judgement'. The lawyer informed us that they had now established that Radhika was mentally challenged and unable therefore to make such a decision herself. They had therefore decided for her and for us. She must try further and prolonged use of contraceptives under close medical and psychological supervision; that in their 'wisdom' they could not agree to the ligation. We argued for a while, getting angrier and angrier at their unreasonable, insensitive approach, but after twenty minutes they terminated the proceedings and dispersed, leaving us shaken and quite distraught.

I had told them what I thought of them in no uncertain terms: how dare they pronounce on us; we who had given eighteen years of our lives to rearing Radhika, we, not they, were responsible for her. I warned that if she got pregnant, I would leave the baby at their doorstep and would sue them as well. Mr Oliver and Jan Duncan had spent hours with us; they were angry too but there was nothing more we could do. The support and understanding we got from the Principal and members of the school community helped a little in assuaging our hurt and frustration.

We were leaving Australia soon after, but Ramesh did write a long and frank letter to the Guardianship Board telling them what we thought of the proceedings and their decision. I hope parents in our position can be spared such a trauma. At home in India, where sexual freedom is not as explicit, we felt Radhika would not be as aroused as she was in Sydney. However, should the question come up again, we would definitely consider a ligation in the belief that, in her particular circumstances, this would be the best solution.

After Sydney there has been no opportunity to develop such a relationship, and her libido has been diverted and

controlled. However, she continues to want a 'boyfriend', looks longingly at her sisters, wants one 'like Aarti's', but insists she doesn't want to marry and leave home. I am deeply saddened to see her in her prime, fantasizing. Her sisters may marry or not, at least they have the choice. She has none. I see no way out. This breaks my heart and the ache goes so deep I would rather not dwell on it.

Chapter Fourteen

The most enriching and rewarding experience for Radhika was her exposure to creative painting at Cromehurst. It took the first year in school for this interest to develop. Soon Radhika began to enjoy painting sessions, creating many varied works of art that gave her joy and made her the focus of much attention and admiration.

Here I must go back in time to trace the start of a very successful art programme pioneered in Cromehurst in the early eighties by Alan Oliver, who subsequently became senior extension class teacher and Pamela Fairburn, artist and teacher in Cromehurst. They used innovative techniques, media and approach to develop a new kind of art whose foundation was freedom.

After two successful exhibitions *Paintworks*, a book on Cromehurst art was published in 1981. "*Paintworks* is a milestone", wrote Desiderius Orban in the foreword. "The paintings and glimpses into the stories behind them show the results that can be gained by encouraging and fostering the creative instinct."

In the preface, Oliver and Fairburn added, "The importance of art education in Special schools cannot be overstressed. The paintings reproduced here provide the most telling evidence of the high standard of creative expression that can be reached by Special students."

In their view, once traditional approaches to painting are overcome, the student develops confidence and his imagina-

tion is stimulated to produce expressive art of a very high standard. The approach and techniques used were structured "to give children with perceptual and/or visuo-motor problems, forms of art expression designed to develop manual dexterity, produce keener observation, stimulate imagination and guide the students to an end result which expresses the subject successfully and creatively for them."

Moreover, in their experience, realistic art dampens the creative spirit, particularly in a child with a mental disability. He cannot do as well as his 'normal' peers, is self-critical though fearful of criticism, and will not paint. This new method finds no faults. The results are stunning, both in the art produced and in the growth of confidence in the student.

By the time we arrived in Sydney in April 1986, the art programme was well established in Cromehurst. Pamela Fairburn had left, and Alan Oliver was doing less art with the students as he was concentrating on preparing the seniors for employment, and giving initial support to those who had found jobs. However, young and enthusiastic Katrina Bull, was the current art teacher and had an excellent tradition to work with.

The weekly art period for all classes lasted forty-five minutes. The youngest children spent most of the time putting on their art shirts, sitting down and following simple instructions. Two or three primary colours were placed in saucers before them and when the music was put on, they had to dip their brushes in the paint and dab their paper to the rhythm of the music. The paper was large, and often each child worked on different parts of the same sheet. They were noisy and untrained; early education was only just beginning. After a year in school, they had made progress in all spheres. They followed instructions more promptly and began to express themselves better. By the time they had reached class IV or V, they were quite 'civilized', and much more capable and

confident.

Radhika attended art classes, like all the others, but for the first six months we were not aware of the very special nature or importance of this class. This became apparent only after the first exhibition held in a local Community Hall. From dozens of paintings the best ones were selected to be framed and exhibited. On the opening day there was a long queue of parents, friends, artists and well-wishers waiting for the doors to open to view the children's work.

Unfortunately Ramesh was out of Sydney for the opening, but Radhika and I were there. With great enthusiasm we lined up to buy her first work of art. I hadn't brought enough money or even a cheque book, and the paintings were selling like hot cakes. Danielle's father came to my rescue. There and then Radhika and I made a pact to pretend that someone else had bought it before we could, so that she could give her father a surprise present on his approaching fiftieth birthday. She was very excited and promised to keep it secret. We told Katrina of our plan, and warned her not to tell Ramesh as he was bound to ask who the buyer was.

We visited the exhibition all the three days it was on. The reviews and general interest aroused was heartening. Some of the older children explained their methods and techniques. It was a tremendous success for all concerned.

Ramesh was disappointed to learn we had not been able to buy Radhika's painting. Predictably, he wanted to know who had; he would pay extra to buy it back. Katrina remembered to tell him firmly she could not divulge the name of the buyer and Ramesh had to content himself with close-up photographs, while Radhika and I exchanged knowing looks. Radhika kept it packed away in her cupboard and surprised me with her ability to keep the secret. On the morning of Ramesh's birthday she got up early, and brought it down for him. His surprise and delight knew no bounds. It was given

pride of place in his study. The photograph was used on our Christmas card that year and went to friends all over the world. 'Reflections' is a beauty. At the time we couldn't be sure if it was a fluke or a one-off, but it has always had a very special place in our hearts and home.

Amongst all the various school activities, the weekly art class was something Radhika particularly looked forward to. She had a good relationship with Katrina based on mutual respect, for Katrina knew how to draw out the best in her and was appreciative. During class they had the radio on a great deal of the time. Sometimes discussions would follow the local news, but most often the beat and rhythm of pop music provided stimulation. There was plenty of paper and a variety of waste products; sand and shells and items collected on their outings; water colours, inks, fabric paints, fevicol and glues, rollers, brushes, scrapers, just about any and everything that could be used. Aprons or old shirts worn back to front protected school uniforms from enthusiastic artwork, while a large sink with running water helped in the cleaning up afterwards. Children worked indoors on long tables, or outdoors, depending on the weather and the kind of painting they were doing. The walls were covered with paintings, and dozens were just piled up on a table — a creative mess, Katrina called it. Most paintings were completed over several art lessons, the children working each at his own pace under the watchful and encouraging eye of Katrina, who all the while talked with them about a variety of things. The art room was a happy and productive place.

During one term Katrina instituted extra lessons after school hours twice a week for those who were specially keen. Radhika happily opted to attend. She was painting a good bit, but only in school. At this time, the General Post Office selected a Cromehurst student's painting for a first-day cover and agreed to host a week's display of Cromehurst paintings

in their central hall. Katrina and 'Ollie' selected the best thirty paintings, and Radhika's 'Outback Australia' was one of them. The exhibition opened at the GPO at nine am — and very early on there was a queue of buyers. Fortunately Ramesh had asked a colleague to get in there and buy Radhika's painting for us as we lived too far out to reach by nine o'clock. As it happened, a gentleman ahead of him in the queue wanted 'Outback Australia', but readily agreed to select another when he was told it was being bought for the artist's father. The paintings were all of an excellent standard and sold quickly. This was the first general exhibition of its kind, and was very successful. For the first time the school gave the artists a ten-dollar cheque for each painting sold, and of course they were thrilled.

The exhibition generated great excitement in the school among both students and parents. The principal congratulated the art teacher and the artists, but pointed out how every teacher in the school had contributed to the development of the students. Moreover, as the school had an integrated approach to education and development, all learning, formal as well as informal, was aimed at increasing all-round efficiency. A successful art exhibition was therefore not merely a success in art; it was a milestone in general development to which every staff member had contributed. Students were constantly being challenged to do better and were surprising themselves and their parents with their achievements. The staff, however, were not so surprised since they knew from previous experience how much the students could achieve.

Some six months later Katrina, bouncing with energy and new ideas was able to get the Menzies Hotel's Gallerie Room to sponsor yet another exhibition, this time for three weeks. Paintings to be hung were carefully selected and given for framing. Radhika never mentioned that one of hers was in, or what it was like or called. Katrina informed us of this. The

opening night dinner was limited to the artists and their parents. Ramesh was again out of town, so Aarti came instead. This time I had decided not to buy Radhika's unless it was something special. We got to the Menzies Hotel in good time and walked down to the Gallerie Restaurant. We were struck by the vibrant and joyous paintings. My eye fell on a beauty. I stared, and asked Radhika if she knew who had done that one. "I did," she said, "It's called '*Hunting in the Snow*'." I was dumbstruck. I just had to have it! Now we had three, each totally different in style, theme, and colours. They were admired by everyone who came to the house. I must not forget to say how extremely mature all the artists were that wonderful evening. They mixed with each other and the parents, enjoying the evening as much as we did.

Later, when Ramesh got back to Sydney, he invited four couples to dinner at the Menzies. Radhika and her friend Arni were there as well. We met for drinks at our home. The girls sat with us and partook in the conversation. It was heart-warming to see our guests make the effort to chat with them. At the restaurant, the girls took us around to look at the paintings before we sat down to order the meal. They studied the menu, decided what they wanted and then proceeded to enjoy the evening.

The first week after school closed for the Christmas vacation, Katrina offered a five-day art camp in school. Radhika jumped at it and at the end of the five days she had done ten lovely pictures. Katrina said hers were the best. Radhika had worked hard with great zest and determination. She was thrilled with herself and all the more motivated.

Several months later, the weekly newsletter announced an exhibition of local artists to be organized by the Willoughby Council in November 1989. Katrina was all for entering the work of her young students. Entries according to age and media used were to be delivered a week in advance. It was

agreed we should exhibit 'Outback Australia' and her monoprint called 'Hunting in the Snow'. Radhika was both excited and nervous when we took them to the Council Hall. She had to give her name, school and home address. She was, as usual, hesitant at first, but stood in the queue and managed quite well when her turn came. On the opening day we were all there: artists, families and Katrina. Walking around the huge room, Radhika showed some interest in the other paintings but soon went off to locate her own. I must admit the Cromehurst pictures were the liveliest of the lot, and when the organizers realized these were the works of children with disability there was a great interest in the artists and their techniques. At the end of the week we collected the paintings, and the Council's certificate of commendation for 'Outback Australia' which was framed and proudly displayed in her room.

In 1990, the Mosman Council held its prestigious annual art competition for young people under twenty. The chief judge was to be Ken Done, the famous Australian artist, and prizes included sponsorships to some of Australia's top art schools. Once again Katrina encouraged her best students to enter their work. Radhika and Katrina decided this time to send in a 'string' painting. There were four to choose from, but as the theme for the exhibition was the local Mosman/Manly area, we selected 'Birdwalk in Taronga Zoo'. Ramesh drove Radhika in pouring rain on the final day for entries and got there just in time. There were four from Cromehurst. The exhibition opened with a tea for the artists and their families; then Ken Done announced the three prize winners. Radhika did not make it this time and she burst into tears. This was an open contest, Katrina explained, and Radhika was fortunate to have had her painting accepted and shown, which was success in itself. Of all the dozens entered only the three best had been given prizes. Radhika regained her com-

posure when Katrina took her across to meet Ken Done. After a short chat with him Radhika took him to her painting. When asked how she had got that particular effect, Radhika explained the technique of 'string' painting. He was impressed never having heard of this before. By the time she was photographed with him she looked happier, as if his attention had made up for her disappointment.

Was it unreasonable for her to expect a prize at this open art competition? In retrospect, I wonder if she understood the difference between 'exhibition' and 'competition'. Perhaps she didn't, or considering its complexity, perhaps we hadn't explained it clearly enough. Her disappointment was very great, and because of her lack of inhibition she had shown it openly. I was a little embarrassed but Katrina managed her extremely well; no childish hugs, just plain talking, and then the introduction to Ken Done. The more our children are exposed to the real world the more it seems they will have to learn to accept that they are a part of it and must not expect 'special' treatment. And this surely is true integration.

'Birdwalk in Taronga' hung in our dining room and was much appreciated by all our friends and guests. There was something quite regal about this bird, and the picture finally found a new home after our return to Delhi.

Meanwhile, Katrina had begun to train senior school artists in demonstrating their techniques to other art students in normal schools and in a few colleges of 'Technical and Further Education'. Radhika was selected to be on the team. The sessions went well. Our artists were excellent demonstrators and surprised the TAFE students with their skill and competence. These visits, the conduct of our children and the comments of those they visited, found their way into the weekly newsletter. Often Radhika would 'forget' to tell us and we only got to know via the newsletter. It carried news to the entire school community, so whichever parent was in

school and for whatever reason, there was always something to chat about with the children. So much happened both in and out of school, everyone was kept very busy.

Katrina introduced the children through their art to an extraordinarily wide variety of people and institutions. As part of her graduating thesis, a student of the Australian Film Institute made a short film called 'With Flying Colours' on the children's art. Another film produced to celebrate Australia's Bicentennial year used Cromehurst paintings in their palace scenes. The Variety Club organized a full day 'Art-in-the Park' session, after which the paintings were auctioned to raise money for the Variety Club; it was a good way of repaying generosity. The Club supported Cromehurst in a variety of ways; for example, a sail on the 'Bounty' for the seniors, and free tickets to a Michael Jackson concert, not to mention a brand new van for their outings.

Chapter Fifteen

Ramesh's heart surgery had been fixed for November 6, 1987 and was now looming ahead of us. He wanted his eldest daughter Sandhya to come from Hong Kong. Aarti was already in Sydney. He was taking it very calmly but I was extremely tense. The girls were my strength and comfort. In the event, the surgery went well and despite some early bleeding, Ramesh recovered slowly but surely. The doctors and hospital arrangements were excellent, and we had great confidence in the surgeon. All the same it was a very anxious time for us. Radhika was keenly aware of our tension. She was very gentle and loving with her father, and gave me an unexpected hug whenever she found me looking grave. She wanted to know what exactly would be done to him, and the purpose of each tube and machine attached to him, in the first few days after the surgery. When he was allowed to walk, she would help him to his feet and walk with him, and every time he held his chest in pain she would look perturbed and anxious.

When Ramesh was discharged from the hospital and came home, the school arranged for Radhika to spend five nights at the school Cottage with her friends, giving us time to settle back. On her return home, she was delighted to see him beginning to look more normal, walk more easily, stroll in the garden, and go up and down the stairs from the bedroom to the living room. She noticed that his voice was now 'so soft and gentle, not rough like before.' Including her in this

experience and in our fears and worries had made her feel more grown-up and responsible. She was helpful and considerate right through. Her teachers and friends in school were given a daily account of her father's progress and shared her concern.

It took three months for Ramesh to recover completely. Fortunately the dry, warm Australian summer months of December and January were ideal to recoup in. Gradually the strain and stress began to recede. He went back to a full day's work by March, and took up golf and gardening. Swimming had been allowed from six weeks after surgery and he had thoroughly enjoyed using the pool in the garden.

During his convalescence, Ramesh's surgeon was on a TV medical programme performing open heart surgery. I didn't know if he should watch it, but we certainly wanted to see what exactly he had been through. Radhika watched it from start to finish as we all did, Ramesh included. We saw what a major operation it was, how skilfully it was conducted, and why recovery from it took as long as it did. Perhaps this reinforced Radhika's dread of operations, but I have felt the children should be exposed to the realities of life, and have exposed her, as I have the other two girls, to everything the family has been through. I can only hope it has been as good for her as I know it has been for Sandhya and Aarti. It has been good for us too since we have not had to withhold information from them and have had their full support.

The family has been close and frank with each other; sharing thoughts and feelings, discussing problems freely, disagreeing on many vital issues. Ramesh and I have accepted the children's choices and decisions. This has been fulfilling because we have remained close through many vicissitudes. With Radhika, too, this approach has worked well. She has faced, undoubtedly, simpler choices. Although it has been easier to influence her, she has liked to be given the chance

to make up her own mind. We have watched her mulling over a problem muttering to herself with a concentrated expression. Often the final decision is ours, but she feels happier having been given the choice and the time to think it over for herself.

The following winter we planned a holiday in the 'Red Heart' of Australia with both Aarti and Radhika. We had a most exciting ten days, driving to Ayers Rock, the Olgas, Palm Valley and through beautiful and unusual scenery we had never before seen the like of. Radhika behaved like a model teenager. She woke in good time every morning, tramped around all day, enjoying the sightseeing, lingering here and there when she felt inclined to.

In an otherwise vast, dry and barren land, there were beautiful 'billabongs', where cool, clear, green water welled up from an underground spring and lay still between the massive red peaks rising sharply into the brilliant blue sky. A few, small dark green trees grew out of the rocks, adding yet another colour to the breathtaking view. In the olden days, wandering aboriginal tribes had quenched their thirst from these cool pools, and even to this day no swimming or fishing is allowed here. We saw several such water holes and were struck by their isolation and stark beauty.

One evening, we visited a recreated aboriginal settlement in the area. Aboriginals lived under the open sky with the barest of possessions and wandered over the enormous area, fishing, hunting the Kangaroo, fashioning their weapons and musical instruments from the wood of local shrubs and eucalyptus trees. We tasted lightly barbecued 'witchety grubs' and found them rather like succulent corn kernels. We watched them make and use their famous boomerang, and heard them blow on their didgeridoos. Radhika showed a keen interest in the wooden artifacts decorated with aboriginal art. In fact, independently of us she chose to buy a pair

of music sticks and a wooden lizard from one such large display. She spent time making her selection, asking the salesman to explain the technique used. We noticed she was beginning to show an interest in how things were made, in the materials used and technique of decoration — a real interest, kindled by the tremendous effort of her school teachers, once again showing how much she could be aroused given the right inputs.

Ayers Rock had to be seen at sunset. It was cloudy the day we were there. Coaches off-loaded eager tourists at the viewing point. All cameras were ready when, suddenly, the sun's rays found an opening in the clouds and we saw the huge sprawling rock. It seemed as if it was illuminated from within; flaming orange to start with, then gradually turning to yellow and purple and finally black as the sun disappeared. It was lit up only for a brief minute but was a truly magnificent sight. It is a 'sacred site' about which wonderful aboriginal legends abound. In that moment we all felt some of its magic.

Ramesh and I did not go up the Rock — he was a heart patient and I a smoker, but Aarti was keen and tried to persuade Radhika to join the group. Radhika being a 'sook', a softee, refused, so Aarti went up without us. It was a tremendous climb to the top and a wonderful experience. We did, however, walk around the rock and took a look at the ancient cave paintings which Radhika found particularly interesting.

Family trips and school outings were used by Katrina to develop themes to be discussed and painted. Thus it was that Radhika's picture 'Outback Australia' came to be painted. The picture vividly expressed the landscape she had observed. The painting looked like Outback Australia — there could be no other title for it.

We returned by coach from Alice Springs. It was a twenty-four-hour journey south to Adelaide and another twenty-four

hours to Sydney in the east. We stopped at Adelaide from where we drove to the nearby Barossa Valley, the famous south Australian wine country. We spent two nights in a small hotel housed in railway coaches. Radhika was most excited. We ate our meals in the 'dining car' restaurant and spent the days lapping up the beautiful rich greens — such a change from the stark bright reds, browns, yellows and blues of the 'Red Heart' of Australia. We visited home-made pottery outlets where Radhika continued to show keen interest. She would ask a simple but a relevant question, listen attentively to the answer, sometimes asking a further question. It was a truly amazing show of interest during that entire trip which she has not been able to sustain subsequently to the same degree.

The coach trip from Adelaide to Sydney was scenically more interesting than the one from Alice Springs to Adelaide. In the Blue Mountains, at eleven pm there was snow on the ground, and snowflakes still drifted down from the night sky. Next morning we were back in Sydney.

Another memorable trip we made was to Tasmania, the emerald island south of Melbourne. We had a week in a hotel on the north coast with Aarti and a family friend from Delhi. We flew into Davenport, hired a car for the week and spent the first afternoon reading brochures and deciding what to see. That evening we drove along the scenic coastal road to a spot which housed a museum of aboriginal artefacts and history. Here we learnt that the last Tasmanian aboriginal had been killed in the mid-nineteenth century and for over a hundred years now, there had been no indigenous population in Tasmania. Radhika could not believe that the white man had 'actually murdered' all the native people.

The sunset that evening over the Tasman Sea was magnificent. Vivid, glowing orange with grey and white clouds over a brilliant blue sea. We stood and watched while the colours

slowly changed and faded. Moved by colour Radhika was visibly excited by the sight.

Radhika had seen limestone caves in the Blue Mountains near Sydney and remembered how dark and damp they were. The shapes formed by the stalagmites and stalactites were different in the Tasmanian caves we visited the next day. The guide pointed out unusual formations and the names given to them. Radhika was as interested as the rest of us, often asking him for further explanations. At the end of an hour of picking our way carefully through the caves, she was relieved to be out in the open again.

In Sydney we had read about the controversy in Tasmania between logging companies and a growing party of 'greens' who, much like India's 'Chipko' movement, were fighting bravely to save the forests. This rain forest spanned a large area in the central part of the Island. We decided to visit it. Cradle Mountain and Dove Lake were on our itinerary anyway, and we had to drive through the rain forest to get to the lake.

A couple of hour's drive through lush green country and we entered what began to look like a desolate ashen graveyard of cut trees and burnt stumps. We stopped the car to look around. Radhika, conscious of environmental issues, was aghast at the bleakness of the scene. It looked and felt as if it had been chillingly devastated by a nuclear blast. Radhika wanted to know why so many trees had to be cut down and why more were not being planted. For a while she became more conscious of not wasting paper, and the need for recycling.

Each day of our holiday was planned and full, and before we knew it the week was over. The flight back to Sydney was bumpy and Radhika and I were uneasy. She clung to my arm and squeezed it harder with each bump. I tried to look calm and reassuring but was relieved when we landed safely in

Sydney. Radhika was full of stories of our trip; the oyster gathering, the aboriginal museums, the caves, the Tasmanian Devil, not to mention the terrible skid the car went into on a patch of black ice when 'mother was driving.'

We have always enjoyed travelling and seeing new places, the girls accompanying us whenever they can. So it was that we organized the next holiday in August 1989 to the famous Great Barrier Reef on the northeast coast of Australia. We were joined by friends from India. Unfortunately neither Aarti in her final year at University, nor Sandhya in a new job in Sydney, could take the time off to join us.

On the day of our departure for Brisbane when I went to wake up Radhika, she did not stir. Patient and gentle for a while, I soon began to get irritated. Immediately she became stubborn and refused to budge. Then Ramesh tried his best, and friend Vee, but both gave up in despair. I was in tears of rage and frustration at her mulishness and obdurate silence. Meanwhile the minutes were ticking by and we could not afford to miss the flight. Finally it was Sandhya who got her up and ready, and we managed to reach the airport just as the flight was being called.

Disappointed and upset, we tried unsuccessfully to find out what Radhika's problem had been. Eventually we decided to forget it and set out to enjoy the trip. Sometime during the trip, after she had relaxed, she did tell us that she was 'afraid of flying, and wouldn't have minded staying home and missing the entire trip.' Her fear surprises me each time and can only be partially allayed by prolonged and gentle reasoning well in advance of travelling. However, surface journeys have held no fears whatever — in fact she just loves them, will be ready in good time and without fuss. Left to herself she'd choose not to accompany us on any air journeys.

It was a marvellous trip for everyone, with lots to see and do. One day we took a catamaran across the clear blue water

around the Whitsunday Island. The crew offered snorkeling, speed boat and 'sausage roll' rides. A pair of inflated rubber 'sausage rolls' were linked to the speed boat, which sped around the water in circles, invariably tossing the riders into the sea. Radhika watched while four tourists sat, two astride each sausage. Away went the boat, pulling them round and round in smaller and faster circles, until they lost their balance and found themselves in the water. When Radhika had watched this several times, she went up to the girls organizing it and said she would like to have a go. We were struck by her initiative and courage and didn't want to dampen her enthusiasm. However, we were scared ourselves for, although she was a good pool swimmer, she had no experience of the ocean. After a quick consultation with Ramesh I explained her disability to the organizers who said they would seat her with a seasoned adult. By the time her turn came she had changed her mind. I was secretly relieved. Taking the initiative had been a big step for her. That her courage had failed her and she finally didn't make it was of secondary importance. I am sure that if her earlier years had been less protected, and she had more experience of such activities, we ourselves would have been less afraid to let her try them out now.

On another occasion, we took a hovercraft to the Reef. It was a clear warm day. The huge boat was full of happy tourists. It took two hours to get to the Reef and the sea got rougher the further out we went. As we approached the Reef, the water changed colour from clear blue to a magnificent green. The white flecks we spotted were not foam but the exposed parts of the Reef itself. We were all very excited. Our tickets included snorkeling, a ride in a glass-bottom boat, a ride in a mini submarine with glass sides, and lunch. Helicopter rides were also available but these cost extra. Radhika happily agreed to ride in the boats but predictably refused the helicopter ride. The rest of us took both boat and helicopter

trips, and some went snorkeling as well.

The reef was the best I had ever seen. The colours and shapes under water were breathtaking. There was a great variety of fish of all sizes, shapes and colours swimming close to the surface of the ocean darting everywhere. Radhika was thrilled. The aerial view of the Reef was exquisite and very different, but Radhika remained adamant about not flying.

After a wonderful lunch on the boat, it was time to return. We stood on the deck and took our last look at the Reef. The captain announced that if we were lucky we might get to see whales on the return journey. We had our eyes glued to the water. Suddenly Ramesh spotted a huge dark object bobbing in and out of the sea behind us. At Ramesh's insistence the captain agreed to go back even though we were running behind schedule. We could hardly have imagined we would see one, let alone a whole school of whales, cavorting in the water. We stood riveted until the captain announced we must continue our journey.

After this trip, several of Radhika's paintings captured images of the underwater scenes and the whales. It was not that she consciously set out to paint what she had seen. It was rather a subconscious use of colours, shapes and movement. When the picture had been completed, it reminded her of what she had seen. Suitable titles readily presented themselves after the customary discussion with her classmates and art teacher.

We were also fortunate to be able to visit Brisbane during the World Expo. Aarti and Radhika were with us. It was a remarkable experience, opening our eyes to many countries, peoples and cultures. The Australian pavilion with its beautiful 'dreamtime' depiction of the aboriginal view of life was particularly memorable. Radhika wandered with us from early morning to late evening on all three days. The fourth day saw us at the Sunshine Coast, well known for its surf and

excellent beaches. Radhika produced no pictures directly associated with this trip. However, her exposure to aboriginal art certainly inspired her use of colours and the dots and circles with which she began to embellish her paintings.

Of our three children, Radhika has had the most varied experiences and travel opportunities, and undoubtedly been enriched by it. Her sisters have never resented this, although I do recall their occasional chiding. "You are a lucky girl, Radhika!" She has been lucky in many ways. I have to remind myself of this when I feel sad about her future, or her loneliness and lack of friends. However, she seems happy enough to watch videos alone, or chat with our friends. Perhaps we feel more hurt for her, than she does for herself.

Radhika's handicap has not restricted our family life or narrowed down normal family activities. This has been possible through the unequivocal acceptance of Radhika by all of us. This does not mean that full acceptance is easy to achieve, nor is it achieved in one go for all time. Again and again one is confronted by the complexity of full acceptance. Who knows when 'full' acceptance will finally come or how long it will take. The journey is all.

Chapter Sixteen

Radhika was considered ready to move up to the Extension Class when she was a confident young lady of nearly seventeen. The Extension Class was the seniormost class at Cromehurst, where students spent their last years in school learning to 'extend' their skills, as far as possible, towards eventual employment and semi-independent living in the community. They were now treated more like adults, given greater responsibilities, and expected to behave in a more responsible manner. They called their teachers respectfully by their first names and had to begin to choose areas for possible employment. All of them were given small but regular jobs within the school. Radhika chose to assist the Class I teacher on Thursdays. Mr Oliver, 'Ollie' to his students, was their class teacher. Besides preparing them for work and life once they left school, he was a remarkable friend to each of them. All the youngsters enjoyed his lessons, loved his jolly ways and looked up to him. Radhika certainly did, if a little in awe. We too were told to demand more adult behaviour at home, and not to talk down to her as was our habit. When she had an image to live up to, she generally did better and this was to be encouraged.

Each year the extension class was taken on a week-long trip out of Sydney. Radhika's class went up the north coast, Mr Oliver and two teachers accompanying the twelve young people. A route map was sent home in good time for parents and children to discuss places of interest and locate them on

an atlas. Along the way, each child had to use a public phone to speak long distance to home or school. Radhika told us how on their last evening a bush fire raged quite close to their camp site. Fire-fighters had landed by helicopter on the grounds of their camp, causing great excitement and they had to evacuate the area. I wonder if this experience was the source of her later painting called 'Fire in the Forest'.

Teaching in the Extension Class was geared to enhancing life skills and making the youngsters more adept at coping in an adult world. Spellings were dropped in favour of recognition of common words at a glance, number work gave way to recognition of real money and simple calculations necessary for small supermarket bills. Time was spent in developing adult conversational skills, sorting out personal and interpersonal problems and discussing everything they would need to know when they were placed in jobs. We found the methods used for such teaching novel and effective. She became so quick and good at recognizing words put on the blackboard that Ollie invited us to come in one morning and observe how well she was doing at this activity. However, money and bills still baffled Radhika. We had not given her enough regular practice. Her lack of training showed up whenever she and other seniors went to the shops to buy their lunches. Unable to calculate, Radhika was being overcharged by an unscrupulous shop assistant. Finally she and I visited the shop together to make a list of prices so that she took only the exact amount required to purchase the snack and drink she wanted.

In class, Katrina and Ollie had a bag full of actual coins and notes. Recognition games were played daily, then adding up to one, two, five, ten and a hundred dollars. The students sat around a large table and each contributed when he could. This group activity challenged, encouraged, and taught, without being didactic or showing up individual weaknesses. Some

students were quick and loved the challenge, some were slower and had to be prodded. The teacher conducted the class in a matter-of-fact way. The school motto of 'Catch them doing something right' infected the whole atmosphere. The consistency of this approach was a lesson to us.

The struggle to help her learn to do the most simple shopping continues right up to the present. One recent example will suffice to show her complete innocence of the skills required, and the magnitude of the task before us. In the Lodhi Gardens one afternoon she decided to have an ice cream after we had walked past the vendor. Her *nani* gave her twenty rupees for two and she walked back to buy them. We waited for her to return. Ten minutes later, she was still there. Sensing a problem I started towards her. The ice creams she had asked for cost more than she had, how much more she had no idea. She could not think what to do and stood looking at the vendor who stood looking helplessly back at her. She could have settled for less expensive ice creams, waved to me for help or run back for more money. But she just stood there as if waiting for a miracle. And finally the miracle appeared in the shape of her Mum. No amount of repeated explanation has helped her comprehension of money.

Telling time has also been hard for her. Ollie found she had an adequate knowledge of school and home routines and could get by without wearing a watch. However, since the age of fourteen, we have coaxed her to wear a watch, to learn to read the time and relate it to activities she is involved in. She has succumbed to pressure off and on, but just doesn't want to wear one as a matter of routine. After two years as teacher's aide in Vasant Valley School, she was finally able to explain her reluctance to wearing a wrist watch. "Children will keep asking me the time", she said, adding "they will tease me if I don't answer quickly." Quite naturally she

wanted to protect herself from such embarrassment.

As a child she was unaware of the differences between herself and her normal peers. However from her late teens she had become increasingly conscious of the now widening gaps. While she found simple ways of protecting herself, we also had to take care not to discomfit her, particularly in company. Reconciling her childishness with her need to be grown-up meant that we had to be sensitive to this contradiction, sensitive in the positive way her teachers in Australia had been.

In school hours she was kept stimulated with class work, weekly cooking and art lessons, her 'job' in Class I, and the weekly outing which now took in visits to supermarkets and offices where some of her friends were already employed. She also enjoyed working in the school canteen started by Danielle's mother. The Extension Class made the sandwiches and executed and delivered the orders to staff and students in time for Monday lunch. With practice students became quicker and better at reading orders and filling them out, but were too slow to deal with the cash. This was handled by the mother on duty. If employers could be persuaded to give our school leavers a chance, this skill could open new job opportunities in the city's many sandwich bars.

In preparation for jobs after school, the maturer senior girls were assigned one school day a week as teacher's aide in Class I. Radhika's turn was fixed for Thursdays. She had to assist with Class work, play, toileting etc, and escort the little ones to the art room, where Katrina found her 'capable and useful'. The school took ten dollars a week from the parents to give to the aides as salary. Unaware of this arrangement, but earning ten dollars was a great stimulus. Radhika had 'earned' this, so was motivated to do a good job, and enjoyed the coke or hamburger she could buy with 'her own' earnings. This job continued through the senior years. Boys

and a few girls were placed in local supermarkets, while others got temporary assignments in publishing houses or the Chatswood Industries, a packaging house specially set up by erstwhile Cromehurst parents for their youngsters after they left school.

Ollie in particular, spent a lot of time locating and convincing local businesses to give our youngsters a chance to prove their capabilities. Once they agreed, he went along with the youngster, stayed on to show him the ropes, and visited daily until both employee and employer were satisfied. This was no mean task, and involved Ollie in a lot of extra work, but knowing the importance of these placements for his students, he did it with great willingness. Once a youngster was properly settled, Ollie would drop in occasionally to find out how things were going; this was all part and parcel of the school programme and the end to which everyone worked, namely, to train and groom these adults to take their rightful place in society, earn wages, prove their abilities, and gain social acceptability.

There were lapses from time to time, due mainly to a lack of understanding but seldom due to wilful disobedience or negligence. Every student knew how difficult it was to get work, and how important it was to be punctual, disciplined, attentive, hard-working, polite, cheerful, neat and clean; that if they didn't prove they were worth keeping they could be sacked like anyone else. All this was discussed with them in school; every experience was shared and lessons learnt and stressed.

In times of recession, it was even harder than normal to get jobs; retrenchment affected our youngsters worse than others, but these things too were discussed, explained, understood — "We have to work twice as hard, maybe for less money and longer hours, if we are to retain our jobs." Thanks to all this preparation and work experience, Ollie and

the school were instrumental in finding permanent placements for most school leavers according to their abilities and preferences.

Further help came from 'Job Support', a fairly new organization in Sydney. It had so far functioned in the western suburbs, providing a much needed service to young people leaving 'special' schools. 'Job Support' employees worked first with the staff to identify skills and interests of the senior students. Then they sought suitable placements in the local community: shops, offices, restaurants and so on. Once the employer was agreeable, a 'Job Support' worker would take the student to the work place and teach him the job over the next three to four weeks. The supporter would also liaise between the employer, the employee and the school, ironing out difficulties and ensuring a smooth working environment. This 'support' was gradually withdrawn when the student-worker was able to manage independently and confidently and the employer was satisfied with his work.

'Job Support' was now in a position to extend its services to special schools in our northern suburbs, and would clearly help a very overworked Ollie as well as provide support to the parents. Radhika was considered a good candidate for 'Job Support's' help but she still had another year and a half at Cromehurst. Normally young adults were ready to leave school at the age of eighteen, but Mr Johnson and Ollie both felt that Radhika needed the extra time to develop her potential further. In fact we all wished that she had been able to start at Cromehurst at a much earlier age. We could see the difference between her development and that of someone like her friend Arni who had joined in Class I.

Radhika was so well adjusted by this time she happily took an active part in everything the school offered even after normal hours. Social evenings and dances were the usual draw, and she even joined the computer class, learning to

work on it in a simple way. She also took every opportunity to attend all extra art classes offered after school.

Sydney parents spent a lot of time driving their school-going children from one extracurricular activity to another. It was fortunate there was so much on offer for our children as well. Active himself, Ramesh always encouraged participation in every activity and readily took on the extra duties involved. So it was that Radhika joined the special Girl Guide group meetings on Saturday mornings. She and two classmates went regularly for three years and derived a lot of fun out of it. The annual two-day camp was the highlight of the year. Radhika got her own overnight bag ready and said goodbye to us almost too cheerily. She loved the music, dancing, camp fires, barbeque meals, the company of her friends, and being away from her home and parents.

On one occasion she had shared a room with a school friend, and there had been a problem between the two. According to Radhika, one night her camp mate had tried to 'squeeze' her throat. Radhika was able to go and tell the supervisor, who had scolded the 'naughty girl' for her bad behaviour. Radhika was very upset and kept repeating, "She shouldn't have done that. I nearly choked to death." She talked of this incident for weeks. The friend was 'dropped' for a while. I used to worry about her squabbles and fights, until another mother said to me that they must be allowed to choose their friends, and fight or make up as they pleased as this was natural and normal. And of course it was.

After nearly three years of Guiding, she decided she had enough and dropped out. Danielle and Arni had also decided to do the same. Once she has made up her mind, Radhika will not budge. Often she cannot explain 'why', but nonetheless is sure of her mind. For example, in the very first few months at Cromehurst we saw a musical by the Merry Makers, an organization providing another social and inter-

est-based activity for the mentally challenged. Radhika loved music and dancing, and went to each show the Merry Makers put on, but consistently refused to join the group and no amount of persuasion changed her mind.

She played netball during the winter season, again with Danielle and Arni and two or three other 'special' teams. Apart from learning to play the game, they developed a team spirit, met normal young people and had something worthwhile to do on Saturday mornings when school was closed. Ramesh and I didn't normally stay to watch. Once when we did, we were lucky to see her catch and net the ball. Her delighted grin was a treat to see. Tonny, the coach, became a special friend who chatted them up whenever they ran into him at other times.

Apart from the activities organized by various institutions, we parents too organized what we could for our children to meet over weekends or long holidays. Visits to each other's homes, the occasional dance or birthday party, going to the movies or the theatre, swimming or tennis meets were arranged whenever possible.

Danielle's parents were keen tennis players and arranged lessons on their home court for Danielle, Radhika and Arni. A lovely young teenager gave them practice on Friday evenings after school. It was good to watch their slow but distinct progress. The forehand came more easily than the backhand, which was a fluke whenever it came off. Good exercise for the girls, it increased eye-hand coordination and concentration and was a pleasurable way of spending an hour with friends. Danielle's mother and I would watch and encourage from the side, while we exchanged notes about common problems with our daughters. This was necessary for us to do because our young people were unable to organize social activities on their own.

Radhika had also been persuaded to join an open squash

coaching scheme for young people. This was held once a week at the public courts near Killara. The coaches were young squash enthusiasts, who were teaching others to play and earning pocket money for themselves.

All these opportunities for out-of-school activities added to the general wellbeing of our children and exposed them to 'normal' people and normal situations. As a result of being able to play squash, Radhika would now and again get a game with her sisters or with her father, which she enjoyed immensely. Ramesh was disallowed competitive squash after his surgery, but could give Radhika a good game every now and then.

Twice a year, the Education Department sent special swimming coaches to Cromehurst to give two weeks of intensive swimming lessons. Every child had to participate, and progress charts were kept on each child. Children learned to swim faster, longer and in different styles, the older ones were taught some life-saving skills as well. Radhika not only enjoyed swimming and these extra lessons, but was also able to compete with some degree of confidence because of the intensive lessons she had with Mr Wright in Hong Kong.

She had become such an active girl by now that she was much easier to motivate. Thus one year we persuaded her to enter a swimming competition, a run-up to the 'Special Olympics'. Radhika agreed. Aarti and I drove her to the pool. She was registered in two races, fifty metres freestyle and fifty metres breaststroke. There were lots of participants and several races. She was nervous, needing to go to the toilet often. Then her name was called. She had seen other races start with a pistol shot. We stressed to her that she must not dawdle; at the sound of the shot, she must go for it, stick to her lane and not look back or sideways till she reached the finishing line.

We sat back and waited. There she stood with the others.

She had never swum anywhere near fifty metres in one go before; she was usually slow off the mark, and invariably lost speed by turning to see where the others were. Bang! She was off at once. She never looked up, but kept going and thrilled us all by coming in first! We rang home at once and urged Ramesh and her *nani* to come quickly to watch her second race. When this was announced she was more confident. She swam well and this time came in third. Then followed presentation of certificates, handshakes with the judges, much applause and photographs by proud papa. We were particularly glad to have seen how determined she was, and how steadily she had swum the entire length. Her name and success appeared in the following week's school newsletter and she was as pleased as punch with herself.

Every year, during the long Christmas break, Cromehurst ran a month's summer school. They took in their own students, and any siblings who wanted to join. The idea was to give the children a good programme and their mothers some relief. Radhika went twice and enjoyed herself, but the third year she didn't want to go. Instead, she went to work in Ramesh's office where she carried the mail to the various departments, made and served coffee and learnt to photocopy. She felt very grown-up, behaved appropriately, did a reasonably good job and thoroughly enjoyed the exposure. She must have talked about this in school, since several young men there told me they wanted to work in 'Mr Chand's office' as well. Ramesh had been hesitant to let even his daughter come in to help but had relented, realizing the value of such an experience.

Chapter Seventeen

On her health front several problems surfaced which needed attention and caused us some concern. The developmental teacher at Cromehurst felt that Radhika may have a problem with her eyesight. She recommended a specialized eye check for visual acuity. It revealed a moderate amount of long-sightedness and restriction at the reading/writing distance. She was prescribed exercises and spectacles to improve focussing flexibility and reduce stresses of close work. She didn't like wearing them, could hardly keep them on because of her tiny ears and flat-bridged small nose and soon put them away in the back of her cupboard. The comprehensive tests she was given could give no information "as to whether or not meaning is obtained from what is seen, how much effort is required to see clearly, or whether or not vision is more efficient using only one eye as opposed to using both eyes together." The implications of the full report were quite formidable and would require determined effort and time if we were to undertake the regimen advised. It did indicate difficulties in vision which together with her mental handicap made reading far too laborious.

In addition to this difficulty, as our children grew up, they wanted books with more grown-up themes. These were just not available in clear, large enough print. I looked in vain in bookshops in Hong Kong, Sydney and even London and had they been available, Radhika might have continued reading. The school faced the same difficulty, and depended on con-

versation and TV programmes to fill this gap. Now, Radhika reads only when we can find her a suitable story in a clear enough print. Since this is rare she has gradually lost the habit.

Over the years, Radhika has been moved by stories of courage which have only been available to her on TV, video or the big screen. She watches almost anything, from serials, murder mysteries, thrillers and romances to true stories of courage and heroism. Movie-watching seems to be less taxing than reading and therefore more pleasurable. In Sydney we got her interested in good cinema and found she thoroughly enjoyed films like 'Dead Poets Society', 'My Life as a Dog', 'Cinema Paradiso', 'My Left Foot' etc. Looking back, those were full and happy years.

Down's children suffer from both visual and hearing problems and before long we were advised to get her hearing checked. Fortunately, this was found to be normal. Earlier, in order to ensure Radhika's safer participation in the school's active physical education and sports programme, we were advised an X-ray of her cervical spine to check for possibility of any weakness or abnormality in her atlanto-axial joint. Fortunately, this too was normal. However, her feet were not, and needed attention. The deformity seemed to be increasing, resulting in sore and calloused feet. A visit to the local orthopaedic surgeon was arranged through the school. Specialized devices known as night splints used to correct or contain the problem had made no difference. Six months later, Radhika was prescribed special shoes fitted with valgus waste pads, and operations on both feet, back and front. This put us in a quandary as it was a complicated surgery involving hospitalization, anaesthetic and longish period of recovery during which she would miss nearly eight weeks of school. We agonized over the decision until we thought of asking the surgeon about possible side and aftereffects. He informed us that rheumatism often resulted. This made our decision clear:

we chose for her only to wear the special shoes, in which her feet had enough space and support to be comfortable. Her tender-hearted father has often wondered how she manages walking and playing games without ever complaining.

Sometime later she mentioned she had a boil under her breast. She has had plenty since then, under and between her breasts, in her groin and in her armpits. She has them just before, during and after each period. Homeopathic treatment in Sydney and Delhi has so far made no difference. They are fairly large, quite painful, and ooze a thick yellow pus when they burst. Sometimes, she gets frustrated and admits she has given up on doctors. Generally she has been extremely long-suffering and uncomplaining. We still don't know what is causing them or whether she will ever be rid of them.

Another problem surfaced while we were in Sydney, this time from her teeth and gums. We noticed blood stains on her pillow and a thick gum-like coating on her teeth when she woke in the mornings. No wonder her mouth smelled. Yes, this was the result of the spongy gums also associated with Down's Syndrome. She would need to brush more carefully and more frequently, she would also need to visit the dreaded dentist more regularly, and be more conscious of her mouth and breath. Is there no end to the amount of extra care she is required to take, no end to the supervision needed? The great variety of difficulties she deals with on a daily basis makes us marvel at her cheerful acceptance. I am sure that very few normal people could take all this with her equanimity, and yet remain as active and joyful as her. It is this, together with her tremendous determination to learn to do things herself that commands respect and admiration, and is at the core of the humbling experience she has been for us.

Chapter Eighteen

Radhika waited for her birthday each year with great impatience and excitement, and we never failed to celebrate it. She made the guest list herself. Mannix always topped it though she said she could not 'stand him.' He was great fun and a compulsive talker with very winning ways. She would list her favourite staff, principal Johnson, all the classmates, and a few others she was friendly with. She also had her favourite menus. The girls and I would get the evening organized, complete with balloons, streamers, dance music, games, videos and lots of food and drink. The guests arrived with Radhika straight from school. This meant tea, then a swim, some dancing or games, then dinner and cake. The youngsters were collected around nine-thirty pm. Radhika would invariably have Aarti and Sandhya and a friend or two of theirs, and they happily joined in. Their presence and participation made the party greater fun for everyone.

Cindy loved these gatherings too; she hung around, was fed, loved and played with. The vigorous dancing enjoyed by most kept them busy for hours. Sometimes Radhika would turn off the lights. Once, I remember Sandhya coming up to tell me the lights had been dimmed, and Radhika and boyfriend were cuddling up on the sofa.

"Ma, you'd better do something at once," she said anxiously.

I did turn the lights up and they moved apart, although I remember feeling that this interference would not have been

necessary had it been a party for normal seventeen-year-olds.

The teachers would come with the children, participate in all the dancing and the games, sing 'Happy Birthday', and 'For She's A Jolly Good Fellow' (invariably at Radhika's own insistence) and keep a watchful eye on everyone. These evenings were very popular as everyone had a good time. The young people were well behaved, helped to clear up afterwards and said their thankyou's and goodbyes politely. It was quite revealing to observe the fairly normal dynamics of the group. I wonder, perhaps, whether it is not us parents who make too much of their disabilities.

Two or three of Radhika's special friends would spend the night after the party. The girls sat around together, chatted, watched TV, discussed the party and finally went up to bed. Next day we would eat a jolly breakfast and then say goodbye.

Some of the girls had become quite self-conscious, though the boys at the same age were still childish. There were definite eyes made at Sandhya and Aarti's young men friends who took it all in the right spirit. Like their siblings, these youngsters too wanted to go out with their friends and have the occasional parties and get-togethers. Several parents said how much they appreciated the effort we made, and we could all see that the children had certainly enjoyed themselves immensely.

Radhika is a great party person, always ready for a party — her own, ours, Aarti's or Sandhya's. There was an official dinner coming up. I had had her ten new paintings framed and Ramesh decided to replace all our decor with her latest pictures. The existing nails were used, and it took us a while to find the right spot for each picture. After hours of work, we stood back to look. What a stunning effect they had. The guests arrived the next day; they noticed the change at once, each one amazed at the variety, colours and style. Radhika went round explaining how each painting had been done and

what she called it. They were as intrigued and fascinated by her explanation as by the painting itself. She looked good, spoke well, and made quite an impression. One lady present who had an art business offered to be Radhika's agent, saying her paintings would sell like hot cakes to corporate offices. There had been expressions of interest and offers to buy her work before this but she had never wanted to part with a single picture. An offer of a thousand dollars for 'Outback Australia' had made no difference to her. They were good, she felt ever so important and we were very proud parents.

In 1987 Radhika said she wanted to start piano lessons again. She had expressed such an interest in Calcutta when she was nine or ten, and had had a few lessons before we left for Ramesh's new job in Hong Kong. Radhika has an ear for music which she loves, so we decided to find her the right teacher. School was the best place to ask, and I went to speak to Faye in the office. We wanted someone who would make it fun, someone Radhika would relate to and enjoy. Faye said she had a very dear friend who fitted the bill but had no experience with special children. Though a little nervous, Maureen was willing to give it a try and so were we.

Maureen lived in West Lindfield, not far from the school. Once a week after school I would take Radhika over to her house. After the first few lessons, Maureen visited the school to find out how to proceed further, how to measure progress. She talked to the Vice-Principal. "It is important to judge progress over one year, not every month. If you remember this, you will do very well", the Vice-Principal advised. Maureen enjoyed the experience and got to know Radhika well. Both teacher and pupil developed a happy relationship which was the basis of many fruitful lessons over the next three years.

It was good when such initiatives came from Radhika herself. She needed to learn that everything has its own

discipline, that it is not enough to want to play the piano; it requires practice, concentration and effort. Piano playing was excellent for Radhika for a number of reasons — visual acuity and flexibility increased in following the music from left to right; for memory and concentration of her mental processes; for finger movement and strength; for eye-hand coordination; for auditory sequencing and memory, and for her self-image in general. She was never going to become an advanced pupil, but she did learn to play tunes she liked once they had been simplified for her. The effort she had to put in was phenomenal, but there were rewards and pleasure as well. As in all such activities, a lot of effort yielded seemingly small gains, but for Radhika these were undoubtedly big ones.

Maureen also taught her to read music. This was hard going and took a long time. As they proceeded, new ways were evolved that Radhika found easier, starting with only the tunes Radhika wanted to learn, initially only with the right hand, and that slowly, very slowly. Radhika concentrated hard for the first fifteen to twenty minutes — you could see it on her face and in her eyes; then, exhausted, she would stop. At other times she found it less difficult and would go well beyond the half hour; Maureen went along with her, at her pace. Sometimes Radhika would freeze, look most unwilling when faced with something new or more difficult. Maureen would remind her gently how far she had come, sit back and give her time. After thinking it over, Radhika would give it a go. Then Maureen would play the accompaniment and Radhika the tune. They enjoyed this and Radhika looked pleased. After a good session she would get off the piano stool, have a chat with Maureen, pat the dog and the cat, say a cheery goodbye and walk out with a real swing to her step. Maureen had become a good friend.

Before long we needed a piano at home and Maureen helped us to buy one. In the second year, Radhika was in-

troduced to playing with both hands. It was difficult, demanding, complex, but Maureen took it slow and steady, always encouraging, and Radhika began to succeed. She learnt to play her school song, various Christmas carols, 'Waltzing Matilda', 'Do Re Me', and other favourites.

Some days she would practise, other days she would refuse. Some lessons went surprisingly well, some poorly. Maureen never scolded but patiently went over the piece again and again and again, until it seemed to click in her mind. Once they played together at a school assembly; Radhika became confused with the children's singing, so Maureen decided to start again. This time Radhika played well and received loud applause. Later, at the church carol service, the Cromehurst staff and students sang and played, Radhika contributing 'Come All Ye Faithful'. Parents were in the audience. There was no outward pressure, no staff member giving last-minute panicky instructions. The children had done their rehearsing and were now left to perform. Matsu, a Japanese classmate and Radhika played a carol each and played very capably. Proud Mamas were grinning happily, while the youngsters behaved with an aplomb good to observe.

Approximately a year after starting, when Radhika had enough confidence she decided she didn't want me to accompany her to her music lessons, and thus another area of her life became private. I must admit I felt a bit cheated but realized this was a natural corollary to growing up and must be accepted as such. During our chats over tea on her return from school, she had mentioned how a friend in school resented his mother's continual interference. "He wants to do his own thing but she won't let him. Poor chap, it's not fair." This child of ours whose future had been uncertain, was now developing her own personality and demanding her own space.

Faye at the office knew all the children in the school, and had observed Radhika from the day she had joined. Whenever I went to school, Faye would invariably have a little chat, often about the enormous change she had seen in Radhika over the years. One day, on her own initiative, Radhika invited Faye and her husband to dinner. Having issued the invitation, she looked at me for confirmation. We had to laugh. Radhika and I decided to invite Maureen and her husband Tom, as well.

Radhika was a solicitous hostess all evening. She took her guests around the house, showed them her paintings and answered their queries. They were very impressed and not by her art alone. Faye recalled what a quiet little 'mouse' she had been when she first arrived in school and now here she was, brimming over with self-confidence. My heart always filled with pride and joy when Radhika was complimented. True for mothers of normal kids, it meant more when it was so hard won.

Chapter Nineteen

Every term, children and their parents were involved in raising funds for the school. Lamington and chocolate drives, swimathons, cake sales, and the yearly fête were regular features. I offered to run a curry stall for the 1987 fête. Twenty kilograms of meat was contributed by one father, and Radhika's family turned it into a delicious vindaloo. On the day of the fête we set up our stall and dished it out to dozens of eager visitors. It was such a success that it was repeated every year thereafter.

These fund-raising activities served several useful purposes. Staff, students, parents, community, all became involved. The children were exposed to speaking about their school to friends and neighbours, thus gaining confidence and experience themselves and dispelling fears and ignorance in the community as they went along. Radhika had been nervous at first. Not wanting to go at all, she kept 'forgetting' till the last day or two. We had to constantly remind, encourage and persuade. Finally on the last day she would be roused to go round the neighbourhood with our maid. After the first two years it became a more familiar activity, and it was not so difficult to get her involved. The community round about the school were used to our children; they had seen them behave more courteously than normal rowdy youngsters and were therefore willing to help with their fund-raising efforts.

One summer, the school decided to raise money through a swimathon. Each student from the youngest to the oldest

was given a printed card and expected to find sponsors, as many as possible per lap the student would swim on the appointed day. Once again, Radhika was slow to start. She had to be goaded to make the rounds. We decided to sponsor each lap she did with a dollar. Others offered different rates; a friend in Melbourne sponsored her at ten dollars a lap. "After all, she won't do more than one", she said.

Participants, families, principal and staff assembled at Lane Cove Council pool. That day there were two other 'regular' schools also raising money in the same way. Everyone was excited, eager and impatient to start — little ones, with armbands or rings, and bigger ones, all in the pool. The pool was fifty metres in length and we wondered what Radhika would manage, perhaps one, or at best two lengths. Mr Johnson was recording the laps at the starting end. Well, Radhika completed one, then two, three and four laps, and still went steadily on and on, with a few stops and rests, finally giving up at fourteen! Mr Johnson simply smiled and said. "You surprise yourself, don't you?" After the swimathon the Lions Club had a barbecued sausage and a cold drink for all the happy hungry swimmers. The cards were completed and signed and returned to the swimmers to collect their sponsorships. What excitement when Radhika rang the friend in Melbourne and told her she had done fourteen lengths and was due a hundred and forty dollars! I can still see Mr Johnson standing there, attentively watching his children, not surprised by their determination or capacity but happy to see them surprise themselves.

The annual Sports day was held at the Oval in Killara on a sunny winter's day. Families and friends were welcome. Students participated in as many races as they could — potato and spoon, three-legged, obstacle, sack, relay and the regular sprints. Sports uniforms, running shoes, and ribbons — red for first place, blue for second, green for third, white for

taking part, everyone collecting ribbons on their shirts. The finale was a staff obstacle race. The children cheered, booed, laughed and loved the spectacle their beloved teachers provided. Prize distribution and an Aussie barbecue rounded off the happy morning.

The very first time Radhika took part in a school sports day was when she was ten and in the special class of Bradbury Junior School in Hong Kong. On that occasion the community had gathered in full strength at the Happy Valley Stadium. There were two 'special' races, one for the girls and one for the boys. When they were announced we could see our children lining up at the start, getting ready to run. Each child was looking at the stands, searching for its parents. The whistle blew and the girls ran off. Radhika was determined to spot us before she finished; she did and waved, got left far behind but carried on with a spurt, coming in last with her arms outstretched to grab her teacher. Mrs Lumb received her with open arms and raised her up to the sound of cheers and clapping. I can still picture that happy scene — first or last was not important — she had reached the finish line and was so pleased with herself.

Radhika had begun knitting at home when we were in Hong Kong. She started with small squares of plain knitting - patiently helped by her *nani* casting on and off and supervising each row. Slowly the knitting became even enough to plan a blanket. Sandhya and Aarti had learnt to knit, making lots of four inch squares with leftover wools; these squares had lain with me since our Calcutta days, and now *nani* generously offered to stitch them together while Radhika knitted long plain blue strips to make a border for the blanket. An ambitious project maybe, but Radhika can succeed when she puts her mind to something. Moreover she enjoyed sitting with her *nani*, both knitting and chatting. After a couple of months the strips were ready and sewn on and we had a

colourful blanket knitted by our three girls.

When we moved into our home in Sydney, she was keen to start knitting again. Using twenty stitches and plain knitting she made short strips for a sleeveless pullover for herself. By now she was hooked on knitting and wanted more. She agreed that a candy-striped baby's blanket for a friend's daughter was a good idea. This piece involved using finer wool, double the number of stitches she was used to knitting and four colours of wool that had to be carried along one side; altogether a more difficult project. However, Radhika showed persistence, enjoyed knitting it and completed it very satisfactorily.

Gradually her knitting projects became still more ambitious. Next, she started on a blanket in strips of different colours, deciding herself this should be for her friend Arni. Since we were leaving Sydney for good, she carried it with her everywhere we went, completed it in a year and took it for Arni when we visited Sydney in August 1991. When Arni came over to meet Radhika, she was presented with this enormous labour of love. Arni was thrilled, giving her a hug and saying she would treasure it all her life. Then the two friends walked down to a cafe for lunch together. It was so good to see how confident and independent both were, and how much they enjoyed meeting each other after the year apart.

Radhika gradually learnt to cast stitches on and off herself and, to do purl knitting. One line plain and one line purl, repeated, made 'stocking stitch' she was told. She wasn't comfortable at first, but was encouraged and finally managed to learn. She now sat knitting in front of the TV. We found she always needed either her knitting or her scribbling pad; indeed I believe this makes her feel more useful, and saves her from trying to take part in family conversations that often are too complicated for her to follow.

Once we were back and settled in Delhi I did try to show her a variation of the purl and plain, and how these two basic stitches could be used to vary a pattern. She was not happy or easy, and struggled with this new pattern until her *nani* realising it was taking the pleasure out of her knitting, persuaded me to give up and let her do what she found easy and therefore enjoyable. Radhika looked ever so pleased that her *nani* had understood her and had spoken up for her.

Radhika continued to knit endless short strips which she refused to put together to any useful purpose. Knitting became rather like her doodling on paper, a repetitive activity from which she will not be diverted. Her sense of achievement might be greater if only we could get her to knit with a purpose in mind.

Chapter Twenty

Ramesh resigned his job in June 1990 and we had till the end of August to tie up everything, pack up and leave for India. We loved Australia but both of us felt sure that India was 'home'. Facilities for Radhika would be limited or inadequate, but Ramesh and I had discussed this at length and agreed that this time we must do what suited us, and that Radhika would have to fit in.

Cromehurst was informed of our decision. They offered to speed up her job experience with two weeks as teacher's aide in a normal nursery school. It was a busy place but the staff and already been exposed to other aides from Cromehurst. For Radhika, it was too sudden and unfamiliar. She was helpful but diffident, and the two weeks sped by too fast. However, it was another exposure and was kind of the school to organize it so quickly.

It was also arranged for Radhika to spend two weeks with her friends in the cottage. Here they could practise self-care, self-help and housekeeping, with visits to restaurants and a bowling alley, and have time with each other. Cottage stays were an integral part of the school programme. From an early age, the child came in for a night at first, gradually extending the stay to a week or two in the senior stages. Apart from learning independence, the children learnt to 'share' and relate to others outside their families. The young adults enjoyed being away from home. Teenagers particularly rebel against parents, and ours were no different. Radhika showed

all these natural impulses in simple little ways. She also told me about various friends of hers who were having problems with their parents, and very interesting these accounts were too. It suddenly came into focus; they needed more time on their own and away from their families. What better place than the cottage, and what better people than good supervisors and their own friends. It was recognized as a natural development and accordingly catered for, giving both youngsters and parents a break from each other.

We began to prepare for our departure in July. We had to find a home for Cindy and one for my Homoeopathic Bookshop. After much thought, Sandhya decided to take on the books. Cindy's home was harder to find. We composed little notices and hung them up in the local market and in our vet's clinic. We got no response. Then we dropped them in neighbours' letterboxes and waited. That fat little beauty of ours ate and slept peacefully while we racked our minds for alternatives. I mentioned it to Faye in the school office one day and she offered to put a notice in the next school Newsletter.

We were phoned right away. Frances helped at the school office and knew Radhika. She came over, and immediately fell for Cindy. We were relieved she had found a good home, but the last few weeks we had her were poignant. Radhika was home when Frances came to collect Cindy. We had done our weeping the evening before. Radhika helped to put Cindy's personal possessions into their car, but Cindy would not get in herself. Finally Radhika and I got her to stop chasing about; we cuddled and patted her, then heaved her into the back seat and Frances drove away quickly.

Radhika felt this very deeply, much more than she could express. I wish we had been coming straight home, but we had decided to visit Aarti, now in Oxford, and travel for a few months before finally returning to Delhi. It broke

Radhika's heart. She kept asking why we couldn't get Cindy back. And now she doesn't want a Cindy-look-alike — another breed maybe, but not a Labrador. When we talk of finding a nice little puppy, she is wary. She would like one, but remembers the pain of parting too vividly. I am not rushing her, though I do think a small dog in our Delhi apartment would be a good friend and keep her occupied, especially as she has no school friends here at all.

After Cindy left our home, we had only a month before we too would leave Australia. Radhika went to school till the very end. She wanted to have friends and teachers over to say goodbye. It was a lovely evening, with the usual fare — dancing, eating, drinking, chatting, video, but this time there were farewell speeches as well. On behalf of the class two friends wished her all the best in India. Then she got up in a most purposeful way. We wondered what she was going to do. She addressed each friend and teacher individually, pointing out some particular characteristic and thanking each one. It took a fair degree of confidence to stand there and go round the room, saying something nice and warm and friendly to each person. We felt a little embarrassed but she continued unabashed. It was such a far cry from her earlier timidity.

Radhika had participated in quite a range of activities in and out of Cromehurst during our time in Sydney. I suppose these could be called extra-curricular activities; swimming, tennis, netball and squash, art exhibitions and demonstrations, excursions and trips, summer school, camps and girl guides. She had gained self-confidence, adjusted to new routines, become more adult and responsible, developed a better defined personality and a sense of humour and wit. We had learned to treat her in a more adult fashion and give her more independent responsibility. Whenever she behaved childishly and we told her so, she would quickly 'tell' herself to be 'grown-up'. It worked very well. We had to insist that grand-

parents and aunts also treat her in an adult fashion, listening to her seriously, not laughing at her sometimes childish ways, and certainly not indulging her.

This is what her principal had to say in his final report:

"In general, we feel that if we had begun to work with Radhika from a younger age, her adult potential would be greater. This belief carries the implication that Radhika will continue to develop if given the opportunity. We would strongly recommend that she be given the opportunity to work, so that the maturing process and her capacity to accept responsibility will increase. She would also benefit from forms of continuing education. This could be in the practical aspects of the formal areas, aspects of her vocational needs, and in the areas of art, craft and recreation."

The last day in school must have been a very sad one for her. I went in to say goodbye and couldn't hold back the tears of heartfelt gratitude. Four such remarkably full years had gone by so quickly, and here was Radhika, a living example of what can be achieved. The staff were there to say goodbye and wish her well. "Drop us a line now and then and tell us what you are doing Radhika." She didn't break down though her heart was heavy. Mr Johnson said we would always be a part of the Cromehurst family and they would want to know how Radhika was faring.

Ramesh had spent long hours videotaping Radhika's various lessons, so she could remember her classmates and teachers and we could see how they taught their students. He even taped her last piano lesson with Maureen. It is really hard for me to sum up what I feel for Ken, Ollie, Katrina, Jan, Faye and all the others. It is harder still to come to the end of this chapter in our lives. A part of us will remain there in Cromehurst forever, as they will remain in our hearts and thoughts for the rest of our lives.

We left Sydney at the end of August 1990. It was goodbye

to Sandhya too, as she had moved to Sydney a year ago. Radhika clung to her and sobbed as they exchanged a farewell hug. The parting was heartbreaking for us all. Radhika travelled with us to Oxford. Aarti whom Radhika had not met since March, was already there, waiting to start work on her D Phil in human genetics. We were looking forward to time together, with family and friends. As usual, Radhika accompanied us everywhere. She enjoyed London's bus and tube rides, and London Bridge that kept 'falling down' in the old nursery rhyme. She was fascinated by Madame Tussaud's wax figures, running excitedly from one familiar figure to the next, and intrigued by the Tower of London. She accompanied us on a car trip through Wales and the Lake District and we discussed the scenery and the sights. After two months in England, we came home via Florence, Rome and Dubai.

In Florence and Rome, we spent each day wandering from one museum or gallery to the next. There was so much beauty to take in. Except that she could never wake up in time to make an early enough start, Radhika walked all day, taking in the art, sculpture and architecture; she never lagged behind and after a short rest was ready to go on. When she couldn't take any more she sat and waited till we came out again. She had her favourite paintings and sculpture and enjoyed recognizing in picture books what she had seen during the day.

Dubai was very different. We saw the desert and the oases and the camels. It was like a geography lesson for us all. We met several old friends who hadn't seen Radhika for years and who were most impressed by the progress she had made. She was interested in everything, often asking relevant questions. On this nearly three-month-long trip we found she adjusted easily, showed a keen interest in everything, never complained or created difficulties, and was good company most of the time. She is lucky indeed to have had so much travel and enjoyed such rich and varied experiences.

Chapter Twenty-One

In November 1990, we were finally back in Delhi. The baggage arrived in December; Radhika wanted to come along on each of the three days it took to clear it from Customs. The container terminal and the proceedings were new to her, but she was interested in everything. Her four-year-old piano created a customs crisis. It looked too new, the officer said. We couldn't believe the amount of duty he wanted to charge, and we couldn't find the bill to prove its age. She was in tears, "I had to wash my hands every time before playing the piano," she said plaintively to the puzzled officer. He eventually accepted our signed statement and did not charge any duty on it.

Radhika missed the structured routine of Cromehurst, her friends and her sisters. She neither complained nor moped, although she watched her Australian videos almost everyday and spent time with the family, knitting, playing ludo etc. She noticed the noise and dust and chaotic traffic and crowds of people. "Why do they knock on our car windows? That's rude," she said of the beggars at big intersections. I explained as best I could about all the differences she was noticing.

In early 1991, Ranjana Das introduced us to *Jan Madhyam*, an organization working for the disabled. We took Radhika to their puppet rehearsals, wondering how she would adjust to such a different programme, run in Hindi. The team of workers were cheerful, young and friendly. They themselves were experimenting with a media education programme to

enhance learning in special schools, with an emphasis on the underprivileged, and a concentration on puppets, arts and crafts. It seemed like an ideal setup for Radhika to join. It took her several months of regular attendance to begin to feel at ease, but everyone was sensitive and understanding. She started painting again, smaller pictures and in a new style, and joined in the making of *papier mache* bowls and plates. Once or twice a week she would accompany the puppeteers to various special schools, but she did not wish to participate in this activity. She found the conditions too dirty and the teachers sometimes too harsh. Her involvement with *Jan Madhyam* helped her to adjust to a very different life in India from the one she had become used to in Hong Kong and Sydney.

We left India when Radhika was just ten and all the crucial early learning had been put in place by Dina in Bombay. The Hong Kong and Sydney years had only added to and built upon the strong foundations laid in India. It was Dina who had emphasized Radhika's potential for further development and imbued us with her belief and spirit. She had shown us the necessity for a positive attitude, cheerful approach and innovative and flexible methods. Therefore perhaps much more had become possible for Radhika than for many of her counterparts in India, who may not have sought or found a Dina and neither been able to have a foreign input.

On our return Radhika was a young lady of nineteen, and while *Jan Madhyam* provided her with somewhere to go and something to do, she definitely needed a fuller day. Besides, her principal in Sydney had advised not only a job for her but also forms of continuing education related to her work and living skills. We started the search by visiting a couple of institutions running schools and vocational training centres for the mentally disabled. While the buildings and play areas were imposing and spacious and the classrooms fairly well

equipped and full of children, the staff and students looked dull and cheerless. The programme seemed to lack purpose, vitality and a sense of fun and enjoyment. It was very depressing and not a bit like what Radhika had been used to. My heart sank. I heard Ramesh saying firmly, "Radhika is quite advanced and self confident. We would rather keep her at home than send her to an institution where she might regress and become 'handicapped'." And so it was decided we must fill her day in other ways.

There may not be a lot of money to put into special education in a country like ours, but I don't think a lot of money is necessary or is the only ingredient to make these schools come alive or to make learning an enjoyable experience. If the staff were to enjoy what they were doing, have a positive approach and a belief in the latent potential of their charges, then the simplest and cheapest aids and experiences could be used to enthuse and enliven, making the whole process joyful and rewarding for everyone. Instead we got the impression that overburdened parents were happy to have any kind of place to send their children to for safe keeping, the staff considered this merely a lowly profession, neither side knowing or believing just how much was possible to achieve with the right approach or how great the rewards could be for all concerned.

Since existing institutions had failed to come up to our expectations, we had to find other ways of filling Radhika's day. She started private lessons twice a week with Ranjana Das who concentrated on 'forms of continuing education', reading, writing letters, money and shopping, telling time, embroidery, art and craft. She was painting at home now and again, producing a variety of smaller paintings in a new style using dots to decorate them with. Her exposure to equality among people helped her to treat her new acquaintances at *Jan Madhyam* with respect and without condescension. She

was agitated by the persistency of beggars at all traffic intersections and disturbed by the endless soundings of horns but quietly and steadily accepted the changes. Months later when Jolly, the coordinator at *Jan Madhyam*, remarked on the dirt and dust around, Radhika told her, "This is India, you have to get used to it," and surprised Jolly no end.

A year later, we revisited Sydney and immediately felt at home. Sandhya lived and worked in Sydney and had taken Australian citizenship so we stayed with her. We telephoned Cromehurst School and they said Radhika was welcome to attend the extension class. She did, for three out of the four weeks we were there. Some of her group had left school; Arni and Tim had full-time employment at a publishing house; Kylie was attending a special typing class at a college of Technical and Further Education; Julie and Michael were full-time with Chatswood Industries (the sheltered workshop started years ago by Cromehurst parents); and Jeremy was continuing his 'paper runs', delivering the early morning newspapers in his neighbourhood and attending school part-time. Tim Hardiman was cleaning floors and tables at MacDonalds, while Mannix worked part-time at his family's petrol station and was part-time in school. Danielle had not found full-time work that suited her; she loved animals but no vet hospital or clinic had been won round yet to giving a job to a person with a disability. Byam had moved with her family to New Zealand. So most of Radhika's classmates were now no longer in school; she knew the younger ones who had moved up, but her 'mates' had gone. Still she was really happy to meet everyone, and that first day when she was seen in school we heard cheerful shouts 'Radhika's come', 'Hello Radhika.' She enjoyed meeting all the teachers she had known and attending Katrina's art class in and out of school. A three-night stay in the Cottage with her friends was organized for her which she enjoyed very much.

After three weeks she had had enough and wanted to spend the last week at home with us. Ollie told us how hard the recession had hit them. Jobs were even more difficult to get and, had Radhika been there, she too would have faced the same hardship. That wonderful full life provided by Cromehurst could not and did not go on forever. The highlight of the trip was meeting Cindy again. She was brought to the art class one evening when both Cindy and Radhika fell over each other in an ecstatic reunion.

Radhika enjoyed living with Sandhya, going out on weekends, using trains and buses, going to her favourite shopping malls and restaurants and meeting some of her buddies. Sydney was so easy to get around in, Radhika did ask why we couldn't just stay on. When I explained that she was too old to be in school anymore, that her classmates had all dispersed, and that jobs were difficult to find, she agreed that Delhi was better. And we left it at that.

Back at home, Radhika's Australian paintings were much admired by Jolly and Ranjana from *Jan Madhyam*. Discussions began on an art exhibition they would help us arrange. Which gallery? Should we try for the India International Centre? Was it to be an 'awareness raising' exercise? If so, we would have to focus differently. Jolly wanted very careful consideration before the final decision was taken. I tried to discuss it with Radhika but she broke down and wept, making it clear she did not want the focus on her disability, and quite right too.

We knew Krishen Khanna, one of India's leading artists, and asked him and his wife Renu over to advise us. Radhika was nervous and stayed in her room. They looked at each painting carefully. Krishen was impressed. "She is a serious mature artist and must be displayed professionally. Her work stands on its own merit. There is no need to mention, let alone focus on her disability," he said. He told her he liked her

work. Now she felt she could come out and sit with us while Krishen chose the pictures to be framed. It was hard work to leave any out. "They must be framed professionally too," and he gave us the name of his framer. "The announcement must be designed professionally — no question of fond parents showing their daughter's work," he advised.

We were taken aback. We loved her work, but here was praise from an established artist. We were also quite out of our depth, but Krishen said he would be glad to help. He put us in touch with Suhash Nimbalkar who set to work on the invitation card.

Ranjana Das suggested we approach the India International Centre for their exhibition room. We were pleasantly surprised when their Programme Officer not only showed an interest but asked for slides of the paintings to show the Centre's Director and their art critics. She herself did not think there would be a problem in their sponsoring Radhika's exhibition. Several weeks later, when we returned from Sydney, we received their confirmation that they would host the exhibition for three days in January 1992.

Nearly twenty pictures needed framing, and all of them had to be photographed in colour for our record, and some also in black and white to be used for the 'press packets'. Both jobs had to be done professionally. A lot of time was spent in selecting the mounts and frames because we realized that the pictures would look their best if properly framed.

Before long, Krishen's page on Radhika's art arrived. How sensitively he had reacted to her pictures, and how beautifully he had expressed his feelings. There is no better way of sharing it, than reproducing it in his own words:

Our appetites have become a bit jaded with so much passing off as Art which is pretentious, pompous, didactic, inept, full of kitsch, sodden with fake anguish and riddled with a boring capacity to slavishly imitate. The ultimate desire

being to produce an object of easy acceptance.

How far removed are these paintings from the current flood. There are no messages or profound hidden meanings. They are not even painted with you, me and others in mind but are still evocative of a shared imaginative experience. They are straightforward explorations of an imaginative young mind dealing with the form yielding capabilities of the materials she handles.

The image is never rigidly established and then painted in nor is it superimposed on what may have been started off as an accident. It flows from the marks made whether by accident or intention. Nature has endowed her with a strange ability to circumvent the inhibitions of an adult mind. She moves freely without fear, giving rein to her instinct, making her hand follow some mysterious movement taking place in the silence of her mind.

Even her motifs, be they dots or little circles which at times spangle her forms never degenerate into mechanistic devices. Far from their repetitive character becoming boring, they enliven the surface by their changing shapes, sizes, directions and colours.

These pictures communicate in the language of forms and any attempt to decipher them in words must end in absurdity.

Anjolie Ela Menon, well-known artist, Shobha Bhatia, gallery owner, Keshav Malik, *The Times of India* art critic, Malti Nehru from Art Heritage, were all invited to see the pictures and give their suggestions. I will never forget the warm hug Malti gave me, expressing her joy and delight at what Radhika had achieved. Anjolie was quite amazed at her natural gift, colour sense, and the pools of light invading her landscapes. "Art students, in their fifth year, strive to get such effects," she said.

Krishen had a quiet chat with Radhika about her unwillingness to 'sell'. If people liked her work enough to want to

buy and hang it in their homes, this was great appreciation of her art, he explained. He did not push her to decide, but wanted her to think about it. He also noticed that she was jittery and anxious about exhibiting her work. Both Renu and Krishen told her and us that this was only 'natural' as it was exposing oneself to the public eye. Slowly Radhika began to relax, and respond to their suggestions. Their quiet sensitivity to Radhika quite overwhelmed us.

Radhika was distinctly happier to see the paintings once they had been framed. They were done beautifully and looked very good. Now there were so many, we had to line them up on sofas and tables. The photographs were ready too, and excitement began to mount. Krishen had advised that each work be titled, measured, priced and the media used named. Everyone advised keeping the price reasonably low; it was more important for Radhika to sell well than to collect a lot of money from just a few sales.

Ramesh and I spent a lot of time with Radhika emulating Katrina's method of discussing what we could see in each painting and then arriving at a suitable title. With so many to name, this became quite an exhausting business for us all. Help came from Radhika's *nani*, *masi* and friend Vee who joined in the search for names. Asha helped with all the typing. It was touching to be surrounded by so many helpful family members and friends.

As the year came to an end, there was a rush of activity. The cards were printed and ready to mail. *Nani* had her list, my sister Primila had hers. We gave some to everyone who wanted them for distribution to their friends. For weeks we spent all available time writing the cards, addressing the envelopes and mailing them. Radhika signed them personally, and put them into the envelopes; she stuck the stamps on too. When *nani* and Primila visited, we sat around the dining table doing this work. We had decided to use these for our annual

Christmas cards to friends all over India and the world. It was an excellent way of informing everyone of Radhika's 'first one woman art exhibition'. Radhika herself was very pleased and excited, but nervous and apprehensive as well. We had a couple of nasty scenes with her shouting and throwing things, and once even pushing me around. I took her to a homoeopath and with his *purias* she began to relax. It must have been a tremendous strain for her, much more than we realized at the time.

Close family were briefed on their duties during the exhibition itself. We wanted her to answer queries and walk around with the visitors, but not to be hassled by difficult questions from strangers. This would have been far too demoralizing for her, especially as we were not going out of our way to draw attention to her disability.

On January 6 1992, Ramesh transported the pictures to the India International Centre Committee Room. Then Krishen arrived to decide how to hang them to their best advantage. Placing them along the walls, standing back to assess the effect and meticulously moving them around until he was completely satisfied. Once he had decided, the young people got busy helping with the actual hanging. Stands borrowed from UNICEF provided extra hanging space. Radhika spent the whole day at the Centre, sitting and watching. How I wished I could tell what was passing through her mind and heart; she was certainly observing very carefully. She said she thought one lot of four paintings needed more space between them and she was quite right.

In the early evening, Ramesh found her in the lobby, in the centre of a group of tall, middle-aged men, telling them about her exhibition starting the next day. It was a delightful sight. Her spontaneity must have surprised them. They looked puzzled, listened seriously, and not one moved away until she had finished.

Three posters announcing the exhibition and meant for the India International Centre, Lalit Kala Academy and Triveni had a small original 'Radhika' pasted on them. We never thought further about it until the one put up at the Centre disappeared. No, it had not been taken down by the Centre staff. It had obviously been stolen. Radhika was terribly upset. She could not understand why anyone would want to 'steal' it and could not forget this for days afterwards. Other posters were hand-made and written by Ranjana and Radhika, and featured the printed picture of 'Outback Australia' from the card. These were distributed to various shops in strategic markets and to the Modern School in Vasant Vihar for their notice board.

Friends keen to own a 'Radhika' before she became too expensive came over to the house and made their selections before the show. Suman Dubey rang in great excitement as soon as her card reached them; they were all thrilled, and he too wanted to select his painting before it was too late. An Australian visitor to the High Commission in Delhi wanted to buy one after she saw the invitation card. She lived next door to Cromehurst School and could not believe the coincidence. She had a long chat with Radhika and bought 'Rocky Path' done while at *Jan Madhyam*. There were also our favourites which we didn't want to sell. Thus there were lots of pictures with red *bindis* already on them before the exhibition opened.

The India International Centre was a good venue. Centrally located, set in beautiful surroundings, it has all sorts of activities going on all the time, so that a great variety of people come and go through the day. The Centre staff were helpful, friendly and solicitous of Radhika. It was the very first time they had sponsored a show like this, and I am sure they were as excited and pleased with the outcome as we were.

Radhika's exhibition opened at eleven am on 7 January. We got there at ten-thirty to find a few visitors already waiting. We were all rather keyed up. Ramesh had his video camera, Radhika had her knitting. The visitors kept coming, kept her engaged; but at the first lull, she gave vent to her tears. It was such a big event and her heart just overflowed. She was hugged and cuddled and calmed. From then on she was in her element. She held her own, met everyone, took them around the room, stood and chatted and was a pleasure to watch.

"Aren't you glad you decided to show them? How else would you have seen them like this, all talking to each other?" asked Krishen Khanna of Radhika at the start of the exhibition. They looked splendid and Radhika was very pleased indeed.

The exhibition lasted three full days, but Radhika was happy and confident, loving and giving of herself throughout. It was extremely well received; there were many delighted, amazed, proud comments in the visitors' book and there were several people who found they had arrived too late to buy a painting. For Radhika it was success and she was the centre of it. I don't think it mattered to her whether she sold well or at what price; she was really pleased to hear all the praise, and happy to talk about her techniques when asked. She knew, instinctively, that she herself was on show. That was what had frightened her initially, but when she sensed the heartwarming response, she began to enjoy herself immensely. People were visibly moved by the experience; one visitor even ringing me up to say she had felt 'a beautiful, almost spiritual quality in the exhibition room.'

For Radhika it was also an occasion to receive friends and see people she had known but not met in years. Particularly gratifying were the visits and comments from people working with the mentally challenged. The Principal of Aanchal Spe-

cial School and some staff, the YMCA special students and their teachers took the trouble to visit and were full of surprise and praise.

The junior art and craft teachers of Modern School brought two classes of their students and Radhika was delighted to show them round. Subsequently they offered to have Radhika come in and paint under their supervision which proved another excellent experience for her while it lasted.

The important thing in this three-day exhibition was the tremendous spirit of love and sharing; the surprise, delight and joy of so many people who shared with us this great success of Radhika's. The few visitors from the field of special education were not only amazed by the art, but impressed by the artist. I wish we could have reached out to more parents and institutions so that they, too, could have shared in the experience and seen what is possible and how normal a person with an intellectual disability can be.

On 9 January the exhibition closed at seven pm and people came to collect their paintings. Radhika broke down and wept bitterly. She could not bear to part with her pictures. There was no consoling her. She had no concern for the sales she had made or the appreciation and praise she had received. These were her personal outpourings, pictures she had never wanted to part with, but which were now being taken away, some by friends, some by acquaintances and some even by strangers. She was heartbroken.

Radhika's personal triumph and artistic success were the joyful culmination of years of effort on the part of her teachers and family, together with her own perseverance and determination. On show during the exhibition, she proved the efficacy of the approach used from her start in India up to the end of her formal schooling in Sydney. It confirmed that the 'can do' philosophy of Dina Guha does in fact

succeed, especially when reinforced with Ken Johnson's that we must not put limitations on our expectations of them.

Newspaper reports and magazine articles were full of praise for her work and excerpts are included in the appendix. *The Times of India* article was headlined 'Little Wonder', and referred Radhika's art to that of Jackson Pollock's in America. To quote from the article - "And what, to use Pollock's celebrated phrase, is Radhika 'all about'? Looking at the spontaneous yet covertly cerebral quality of the work, it's hard to imagine it's the outpouring of a girl yet to emerge from her teens. Harder still to discover it's the creation of a mind which, in an amazing display of perseverance and grit, has winged its way out of that most inhibiting mental disability - the Down's Syndrome." And perhaps she has, in her own very special way.

Afterword

The inevitable anticlimax after the elation of a most successful exhibition affected us all. Radhika didn't go near her paints for almost a whole year. During this time *Jan Madhyam* offered her only a weekly two-hour cooking lesson. She had one hour twice a week with her special educator Ranjana Das, and one hour a week with her piano teacher Ruth Mehta. This didn't add up to anywhere near enough occupation let alone stimulation.

Twenty years on, with Radhika socially well adjusted and fairly competent, I felt tired out. So tired and drained, I wished I could take a whole year off and away. I felt wrung out, wrung dry, desperate for a long complete break. The years of incessant and detailed thought on what to work at, and how best to work at it — the hard, hard struggle to motivate, encourage, enthuse, had worn me out. I didn't want to think about it anymore. I wanted to escape. I felt I had no more energy, not even the desire to muster the energy. I felt very bad feeling this way and yet, I could see it was natural after all these years. I watched her sitting and knitting, sitting and sewing, sitting and writing, sitting and watching the video and I knew I should be actively teaching her a new stitch, a new design. Challenging her mentally with questions. But I could not muster the will or the energy. Does the need for the effort never end? Does one's responsibility never cease? Will I always feel guilty for not doing enough? Will she begin to slide into mental and physical apathy now that I cannot

push and prod like I used to? Can I live knowing this? Can I feel free for a little while? Free from the responsibility, free from guilt? Will my energy and drive and desire ever return, or has it been exhausted once and for all? My head bursts, it's so full, so heavy, so burdened.

That she can paint beautiful pictures, knit, sew, read a little, write a little, play a few ball games, swim, chat easily with various social groups, look after herself at home. That she has a fairly well developed personality, knows her mind, has a sense of fun and enjoyment of life — all these have been worked for, both by her and by us — and it is a relief and a matter of pride and joy. But I can never be free of responsibility for her like I am free of the responsibility for her sisters. She has been a challenge, a reward, a loving child, a happy child, but she has also been a millstone. As I get older and frailer I will need to find a resolution that is gentler on me, more accepting of her weaknesses. It was so important to help her overcome all her shortcomings, we worked so hard at it, we were so determined to prove that Radhika could learn to be an acceptable member of family and society. We were driven and we had energy and youth and the good health to put everything we had into it. I have felt such exhaustion before, and after short spells, have recovered the energy and desire to get back to the grind. This time I could not seem to muster the strength or effort. It has been over six months already. 'They', those who knew and advised, said that the early years were crucial, that we should pack in all the learning we could because there would be a plateau after that and then the best years would be behind us.

In Cromehurst, they said the potential could not be ascertained, they had observed children make limitless progress with more expected of them, more demanded from them. But Australian special schools take children early and train them till the ages of eighteen or twenty and then help place them

in suitable jobs.

Radhika's parents have grown older and cannot do as much as before. Is this the plateau then? Can she live on her own after us? Managing her finances and her life in sickness and in health. Who will shoulder the responsibility after we have laid down our heads? It is not simple or easy and I have hoped and prayed that she may die before us. If she doesn't, she has two loving sisters, both out of India, each with her own life to live and battle with. Perhaps one or both will have her stay in turn, hopefully her skills will be of some use to them and their families. I hope that her presence, however burdensome, will continue to give them joy, some spiritual reward and enrichment, so that it is not too hard having her and caring for her. Or then as my dear Dr Roy has said, I should leave this alone. "You are not the only person who can look after her. Something, someone will come forward." I must keep the faith.

Postscript

In the course of Radhika's life I have found that when I have been in a particularly sombre and dejected mood, something unexpected and good has happened to lift my spirits and renew my faith. This time in August 1992, it was an introduction to Vasant Valley School through the good offices of Very Special Arts. Ramesh, Radhika and I went to meet the Principal of the Junior School to find out if she would give Radhika a chance as a teacher's aide in their art department. She took us around the school, chatting easily with Radhika all the while, and watching her responses carefully.

The following week she wanted to meet us without Radhika. She was as keenly aware of our need to have Radhika in a suitable placement as she was of the difficulties her staff and students might face. She asked us if we felt there might be any problems. I was confident enough to tell her about Radhika's outbursts of anger and sometimes rough handling of me. She was immediately alerted and wanted to know more. I assured her that Radhika had never been violent outside her home or with anyone other than her mother. She told us she would have to discuss it with the Headmaster and if he agreed, they would like to take it very slowly, giving not only Radhika time to settle in, but also the school community time to accept her. This was just how we wanted it ourselves.

In January 1993 we met the Headmaster ourselves. He was warm and friendly and wanted Radhika to start right away. "I've been hearing about her for the last six months, but

where is she? We want her, does she want us?" Radhika had liked the school, the idea of working, and the gentle manner of the Principal. She was absolutely thrilled to hear that the Headmaster wanted her to start the very next day. Thus a very important door had opened for her at a critical juncture in her life.

We had no difficulty in waking her each morning. She woke cheerfully, got bathed and dressed, did her bed, made her breakfast and was ready to leave for her job in good time. In the art room she did simple tasks of handing out paper and art materials, ensuring the children did their work, and clearing up after each class.

One day the teacher pointed to the nursery class on the ground floor from the balcony of the art room on the first floor and asked Radhika to go down and escort the children up. Radhika went off down the stairs but froze in her tracks when she couldn't relate what she had seen from upstairs with where she was at the bottom of the stairs. When the bell rang and there was no sign of Radhika or the class the art teacher had to run down herself. At this point I was asked to come in to show both Radhika and the teacher how to handle the situation. This was simple for me. I knew I had to point out the classes from the same balcony, as well as accompany her down the stairs to each cluster, pointing out each door with the class number on it. This we did for each class every day for a week and then she was confident and went off on her own. Spatial disorientation is confusing. Actually showing her and doing it with her a few times helps to fix it in her mind. Then she doesn't forget.

Radhika was 'Ma'am' to the children and had fairly good control over them. However, lacking discrimination but feeling a sense of responsibility, she was equally strict with the nursery children as with the older ones. We all had to explain very carefully that children needed gentler handling and that

responsibility for discipline lay with the senior teacher. There were other teething problems that were ironed out as they arose.

In May 1993, Vasant Valley School closed for the summer and we spent a month in England with Sandhya and Aarti. In July when it reopened, Radhika was rightly expected to start from the first day. I was asked to stay on and ease her in after the long summer break. But the very next day, I was told it wasn't necessary as Radhika had quickly and confidently adjusted back to the routine.

By the end of August Radhika decided she wanted to increase her working hours from two to four. Everyone was pleased that the initiative had come from her. She now stayed to eat lunch in the staff room 'like all the other teachers.' This gave her self-esteem a great boost.

A year later Radhika indicated she would like to be paid a salary and wrote this in a letter to the Principal. "Radhika is definitely making a contribution and we would like to pay her", said the Headmaster. If you could have seen her grin when she brought home her first pay cheque, your heart too would have burst with happiness as ours did.

Radhika is now a part of the school family. From her tentative beginning to her current position as a paid helper, she has made a great leap forward. Once again we were very fortunate. Equally, Radhika's upbringing and training has made her acceptable. May God bless the many many people everywhere who have helped us with Radhika.

*Cromehurst Public School
Special Education Centre*

24th August, 1990

Dear Mr. and Mrs. Chand,

In general, we feel that if we had begun to work with Radhika from a younger age her adult potential would be greater. This belief carries the implication that Radhika will continue to develop if given the opportunity. We would strongly recommend that she be given the opportunity to work, so that the maturing process and her capacity to accept responsibility will increase. She would also benefit from forms of continuing education. This could be in the practical aspects of formal areas, aspects of her vocational needs, and in areas of art, craft and recreation.

If, in the course of these activities, you feel that more specific information might be of assistance, please don't hesitate to contact us.

In any case, we would naturally hope to hear from time to time, how Radhika and her parents, who have all become our friends, are making out.

Best wishes from all at Cromehurst,

Yours faithfully,

K.E. Johnson
Principal

*Class Teacher's Report
Radhika Chand
24.8.90*

A self confident and self assured young lady

'Academic' Skills

Reading

Radhika is a poor reader. She can recognise and sound simple words on her own. She has an excellent memory for words which are taught to her as words with structural and visual meanings, and has built up her reading skills around this memory. Radhika cannot use phonics to analyze words she is not familiar with.

Number/Money

Counts well and recognises money symbols. However Radhika cannot understand sequential values in number, and has a poor understanding of money values.

Time

Radhika understands the structure of calendar and 24 hour time.

She cannot read a watch. She is able to organise her 'time' around the activities of her family and school very well.

Communication

Communicates well. Sometimes 'shy' in new situations, often an extrovert in familiar company. Radhika has an excellent

understanding of language. Interpersonal skills with (a) *Peers* — makes friends easily — sometimes “bossy.” Radhika upsets easily when teased. (b) *Supervisors* — Radhika respects authority and aims to please.

Use of telephone

Uses telephone confidently

Independent Travel

Radhika is capable of independent travel. However we had to restrict her public transport activities because of her lack of understanding (at the time) of the need for certain moral constraints.

Work Experience History

12 months (1 day per week) teacher’s aide in class I at Cromehurst School — excellent in this position. Displays a caring authority and an ability to work with handicapped children.

2 weeks (Lane Cove Kindergarten) — Radhika looked good in this position, yet was unable to display the same confidence as she had not mastered working in a new environment.

This is worth pursuing for Radhika.

Personal Hygiene and Grooming

Radhika has a fair standard of hygiene and grooming. Report on Radhika’s advanced living skills in her cottage stay is attached.

Alan Oliver
Class teacher

Cottage Supervisor’s Report — week ending 12.4.90 and 20.4.90

Advanced Living Skills Programme

Personal Care

Showering — much better this time; needs reminding to wash her hair and was lax with drying between toes.

House Keeping Skills

Cleaning — a very good help

Dishes — did this a few times without being asked - very impressive.

Community Awareness

Road Crossing — a fine job

Shopping — most impressive, can shop from small list and handles money fairly well.

Social Skills

Fairly good social skills when Radhika chooses to use them.

General Attitude

Radhika needs much more tolerance with others and learning to accept constructive criticism.

Independent Skills

Made her own breakfast; helped cook a few simple meals.

Activities During Stay

Days out at Darling Harbour and shopping at Chatswood; video afternoons and cooking; dinner out at Kentucky Fried Chicken in Lindfield; shopping daily for meals.

Supervisor
Cottage

Art Teacher's Report 24.8.90

"I have known and worked with Radhika Chand from 1986-1990 at Cromehurst Special School. Over the years, I have seen Radhika grow in confidence and develop into a fine young lady with so much to offer the community.

During 1990, Radhika has helped me as a teacher's assistant in the art class each week with our youngest class at Cromehurst. It has been by far the hardest class in the school to work with and Radhika was wonderful! She is very competent in working with young children, being ready to help in any way possible.

Radhika has exceptional talent in art. Through experimentation with a variety of painting materials, media and techniques, she has developed a style of her own. Radhika exhibits tremendous patience, dedication and enjoyment through her artwork. Even one of Australia's top artists, Ken Done, had to ask her how she had done one of her paintings when it was on exhibition at the Mosman Youth Art Award (an art competition for young artists from 12-20 years of age). He had never seen the combination of techniques before.

One of Radhika's most important art achievements has been in educating others (along with a team of students from our Cromehurst senior extension class). This group of very competent artists have taken a leading role in community education in Australia, in instructing in "Art in Special Education" art teaching workshops. They have been educating

others by demonstrating art techniques and discussing their finished paintings. In the past twelve months Radhika has proven a good teacher in demonstrating art:-

- To: *
- * Art Education students from the University of New South Wales College of Fine Arts.
 - * T.A.F.E. (Tertiary and Further Education) Child Care students from Crows Nest and North Sydney T.A.F.E.
 - * Teachers (Primary and Special Education) in a teacher's art in service for Sydney schools
 - * High school students

I will miss Radhika and recommend her to any future employer. She has a great deal to offer others.

Katrina Bull
Art and Senior Extension teacher
Cromehurst Special School

*The following was especially written for this book
by Radhika's sister, Aarti, who was doing her
D. Phil in human genetics at Oxford University*

Down's Syndrome

Down's Syndrome usually occurs as a result of an error in chromosome separation after pairing (nondisjunction) during cell division in the production of egg or sperm cells (gametes). During normal production of gametes, one copy of each chromosome from each parent is transmitted to the foetus. A foetus with Down's Syndrome, however, has three copies of chromosome 21 instead of the normal complement of two by inheriting two copies of the chromosome from one parent and one copy from the other. Hence, the term Trisomy 21 is also used to refer to this syndrome. Studies with the use of genetic markers to identify each chromosome show that more than 75% of nondisjunction events occur in the production of egg cells. Further, there is a strong co-relation with the increasing age of the mother and the incidence of Down's Syndrome. Forty percent of Down's Syndrome cases appear to be age-independent with the remaining 60% being age-related. Couples with a Down's Syndrome child also have an increased risk of having another one.

Approximately 96% of individuals with Down's Syndrome have Trisomy 21, or three copies of chromosome 21. The

remaining 4% of cases are caused by unbalanced translocations between chromosome 21 and either chromosome 13, 14 or 15. Translocation is a term used to describe the break and mutual exchange of chromosomal material between two non-pairing chromosomes. A translocation may be balanced or unbalanced. In the former, individuals have the complete complement of genetic material, although translocated, and do not have Down's Syndrome. Individuals with the unbalanced translocation, however, have three copies of the long arm of chromosome 21, two intact and one translocated, and consequently manifest the disease.

An important difference between Down's Syndrome caused by nondisjunction and an unbalanced translocation is the mode of transmission and the risk, for siblings of the affected individual, of having Down's Syndrome children. Unaffected siblings of unbalanced translocation Down's patient may carry a balanced translocation but produce gametes with an unbalanced translocation and consequently a child with Down's Syndrome.

Down's Syndrome accounts for 32% of severe mental retardation in children; the single commonest cause by a large margin. Other clinical features associated with this disease are growth retardation, a flattened face, an extra skin fold at the eye (epicanthel folds) and upward slanting eyes. These individuals also have an increased risk of congenital heart disease, leukemia, cataracts and premature aging, and those who live beyond the age of 35 almost invariably show some symptoms associated with Alzheimer's disease. There is, however, great variation in severity of the disease between individuals. One of the contributing factors to this heterogeneity, albeit minor, is mosaicism. Mosaicism, as the name suggests, refers to the presence of cells with different genetic make-up and/or structure. If nondisjunction occurs after fertilisation when the foetus consists of more than one cell, the individual will have

the normal genetic component in some cells and Trisomy 21 in others. This occurs in about 1% of Down's Syndrome patients and results in a milder manifestation of the disease.

Dr Aarti Chand

References: The New Genetics and Clinical Practice, 3rd edition. D.J. Weatherall, OUP 1991 Principles of Medical Genetics.
T.D. Gelehrter and F.S. Collins, Williams and Wilkins 1990.

*An "appreciation" of Radhika's art submitted by
Sandhya, her eldest sister, as part of her application
for admission to a university in the USA*

The art of an 18 year old Indian artist, Radhika, has most inspired me because she has been able to excel in her chosen field, despite facing insurmountable odds. Her paintings are modern and abstract. Radhika does, however, draw upon traditional Aboriginal art, hinting at the influence of her 4 year stay in Australia on her artistic development. One painting in particular that has left a lasting impression on me is titled "Outback Australia." Its colours are mostly of the earth, red, ochre and brown. Shades of green are used to portray the thick Australian bush. The style and impression are that of a landscape, replete with contours. Yet, Radhika has never been a student of geography, and is unlikely to study it in the traditional sense, because she is intellectually handicapped by Down's Syndrome.

The medical establishment in India, and indeed society at large, has historically limited the development of the intellectually handicapped through extremely low expectations of their potential, virtually dooming them to a lesser life. This has placed strong barriers on the acceptance of disabled people into society, thereby limiting their social contacts, and the development of their interpersonal skills. Consistent with conventional wisdom of the time, the prognosis on Radhika's development, rendered when she was a young child, was extremely bleak. She was not expected to master even the

most rudimentary tasks, and her language facility was diagnosed to be limited to a few words. Radhika has proven her doctors and traditional thinking wrong, and has developed her abilities well beyond expectations. Today Radhika is well accepted in social situations, comfortable among people, and very capable of conducting herself with grace, wit and charm. She is also fluent in two languages, and is an accomplished artist at the age of eighteen.

Since Radhika is unable to fully communicate her inner most feelings, she often communicates through her art. She paints spontaneously, and her art reaches out and leaves even strangers moved. Radhika's artistic development was made possible by the nurturing and foresight of her first teacher, dedication and love on the part of her parents, care and support from her siblings and friends, and the positive environment of a special school for the intellectually disabled in Sydney. In the absence of this sustenance and support for Radhika, many of us would have had to look elsewhere for inspiration. In the last two years, Radhika's art has been "discovered" and she has exhibited both in Sydney and New Delhi to much popular and critical acclaim. In recognising her talent and artistic accomplishment, major Indian newspapers and magazines have been particularly complimentary of her work.

Radhika's art has been a triumph in the face of overwhelming odds. It continues to serve as an inspiration for me because it shows the tremendous potential of the human spirit to soar above the constraints placed by those who are rooted in narrow-minded preconceived thinking. Radhika's paintings have been particularly inspirational for me because she is my youngest sister and I have personally invested in her struggle. Through her art I have learnt that the power of love and dedication can break through the strongest barriers.

*Krishna Chaitanya in The Hindustan Times,
New Delhi, January 19, 1992 on Radhika's
first exhibition in the India International Centre,
New Delhi*

"If this serenity recurs in the watercolours and mixed media paintings of Radhika shown at the India International Centre, no reservation lingers, with the viewers, for it is something which has been fought for and won by a girl with the severe handicap of retarded mental development. Should such handicaps be mentioned when the achievement can stand on its own merits? Perhaps it should be, as an example to encourage similar rehabilitation. Radhika has travelled widely with her parents, studied at a special school in Australia.

Spaciously conceived, done with large sweeps of the brush, her Australian landscapes have monumental simplicity in depicting the features of the terrain, the distinction of the planes. And, with its delicate colour and magical play of light and shade, her painting of moonlit woods is one of the finest landscapes of contemporary Indian art."

Indeera Chand was born in Lahore in 1937. After leaving university she taught at the Convent of Jesus and Mary School in Delhi, and after marrying and raising a family worked for Mobile Creches in Bombay and completed a two-year diploma in homeopathy in Sydney. Since her return to India in 1990 she has been instrumental in setting up a monthly social evening for mentally challenged young adults. She lives in Delhi with her husband Ramesh and youngest daughter Radhika.